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Life Interrupted: The Adolescent's Experience When a Parent has Advanced Cancer

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Life Interrupted: The Adolescent's Experience When a Parent has Advanced Cancer

By

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Dedication

This work is dedicated to all the children and families I have had the honor of serving, in particular the adolescents who had the courage to share their journey with us. They remind me everyday the power of love and hope in one's life. I will always carry your stories close to my heart.

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Life Interrupted: The Adolescent's Experience When a Parent has Advanced Cancer

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It is estimated that close to 55, 000 children may experience the death of a parent from cancer each year in the United States. Families with children facing the death of a parent from cancer are a potentially vulnerable population often overlooked by health care professionals (HCP), and understudied by researchers. Little is currently know about how having a parent with advanced cancer affects children and adolescents. These youth experience many losses when a parent is diagnosed with advanced cancer, the loss of a healthy parent, the loss of both parent's emotional and physical availability, and the loss of normalcy in their family lives. Research suggests that adolescents have been the most negatively affected group when faced with a parent's illness. This dissertation will provide a comprehensive examination of the effects of advanced parental cancer on adolescents. A theoretical model will be presented as a guiding framework. This model is based on a prior systematic review of literature involving factors influencing children and adolescent's adjustment to parental cancer. The first article is a systematic review of the current state of empirical literature on the impact of a parent's advanced cancer on children and adolescents. Article 2 offers an inductive content analysis of 7 in depth qualitative interviews with adolescent's living with a parent diagnosed with advanced

cancer. The core construct that organized study results was weaving a normal life with cancer. Our findings shed light on how families managed when the "terminal phase" of cancer stretched on for many years. Implications for HCP's include the need to facilitate family interventions that provide parents and adolescents with a venue to communicate and process the impact of cancer on their lives. Article three utilized a hermeneutic phenomenological approach to discover the lived experience of adolescent's facing advanced parental cancer. Four essential themes emerged from the analysis: *Life interrupted, Being there, Managing emotions, Positives prevail.* The findings in this study underscore the significant impact an advanced cancer diagnosis can make on a family system and suggest that the experience may also have the potential of creating opportunities for growth and well being. These findings indicate that some adolescents are able to find meaning in these difficult circumstances which helps shape their growing identity. The themes of positive growth and gratitude that emerged from this dissertation suggest that this is a potentially powerful protective factor that adolescents use to maintain positive adjustment during a parent's protracted illness. Researchers and HCP's can build on these findings to closely examine the potential for gratitude as a construct in intervention programs for families facing parental cancer.

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Chapter 1

Introduction

In 2011, approximately 1.59 million people in the United States were newly diagnosed with cancer (American Cancer Society, 2011). Of these, an estimated 296,000 were parents with a child under the age of 18 years (Weaver, Rowland, Alfano, & McNeel, 2010). When the number of newly diagnosed parents with dependent children is combined with those diagnosed more than 2 years ago, an estimated 1.58 million cancer survivors are parents living with 2.85 million dependent children in the United States (Weaver, et al., 2010).

Cancer is the second leading cause of death in the United States (American Cancer Society, 2010). Approximately 1 of every 4 deaths in the United States is from cancer. These statistics along with the fact the majority of cancers affecting parents aged 25-54 years old have 5 year survival rates of over 50% means children and adolescents are potentially dealing with the long term consequences of this disease for a substantial portion of their childhood (Osborn, 2007). As cancer becomes more of a chronic issue due to advances in cancer treatment, the continuous threat of a parent's cancer recurring and the threat of death of the parent may cause long term negative psychosocial outcomes for children and adolescents (Huizinga, Visser, Zelders-Steyn, et al., 2011). Furthermore, it is estimated that close to 55,000 children may experience the death of a parent from cancer each year in the United States (Weaver, et al., 2010). Families with children

facing the death of a parent from cancer are a potentially vulnerable population often overlooked by health care professionals (HCP), and understudied by researchers.

During the 1970's and 1980's changes in society in relation to the family unit grew from advances in knowledge of family relationships and child development and it raised questions about the philosophy of care and the design of the health service industry. Family-centered care began as an important concept in the second half of the 20th century at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and the role of families in promoting the health and well being of their children (American Academy of Pediatrics, 2003). Today, momentum for family-centered care continues to build and the principles of family-centered care are increasingly accepted in medical settings. As family centered care is becoming more prominent and is increasingly linked to "quality care" as defined by the American Hospital Association and the Joint Commission (JCI) standards for hospital accreditation, research on the impact of cancer on the entire family system has grown (Cliff, 2012; Joint Commission Resources, 2006; Weihs & Reiss, 1996). The majority of psychosocial research in the past few decades has centered around the impact of cancer on the patient and their partners (Faulkner & Davey, 2002). Although there continues to be relatively little research on the effects of parental cancer on children and adolescents compared to the substantial literature on a family adjustment to a child diagnosed with cancer, there has been a dramatic rise in the last decade (Kazak, 2005; Semple & McCance, 2010).

Researchers acknowledge cancer affects the whole family not just the individual patient (Lewis, 2006). A parent's serious illness can have a profound impact on these children and adolescents and can result in the development of psychosocial problems (Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). Parental cancer is a stressful experience for young people, constituting a potential threat to physical and mental health and normative development. The struggle with a parent's cancer diagnosis can be very alarming for children and adolescents and often result in psychosocial problems such as "anxiety, confusion, sadness, anger, and feelings of uncertainty with respect to outcome of the illness" (Semple & McCance, 2010). Cancer creates many disruptions to children and adolescents normal family routines due to treatment demands, frequent hospitalizations, increased parent care when at home, redistribution of household roles, possible decline in income, and a decrease in the physical and emotional availability of both parents (Osborn, 2007; Semple & McCance, 2010). In addition, research addressing the psychosocial needs of cancer patients has shown over 73% of patients with children desired information and services to support their children and parenting concerns yet only 9% of these families received this type of family centered support (Ernst et al., 2013). Moreover, studies show that due to lack of support, and practical and emotional difficulties children were frequently not prepared for the death of their ill parent (MacPherson, 2005; Turner et al., 2007).

Although it is frequently hypothesized that parental cancer negatively affects the emotional and behavioral functioning of children and adolescents, evidence of this risk is conflicting (Hoke, 2001; Jantzer et al., 2013; Osborn, 2007). It is not clear whether these

inconsistent findings are due to methodological discrepancies in the studies or an apparent resilience of some families. There is some evidence a small subset of these children and adolescents are able to maintain positive levels of adjustment despite the apparent disruptions and emotional strain a life threatening illness imposes on a family. Therefore, there is a need to closely examine risk and protective factors in this population.

Little is currently know about how having a parent with advanced cancer affects children and adolescents. These youth experience many losses when a parent is diagnosed with advanced cancer, the loss of a healthy parent, the loss of both parent's emotional and physical availability, and the loss of normalcy in their family lives (Christ & Christ, 2006; Siegel et al., 1992). Research suggests adolescents have been the most negatively affected group when faced with a parent's illness (Grabiak, Bender, & Puskar, 2007; Lindqvist, Schmitt, Santalahti, Romer, & Piha, 2007). Findings suggest adolescents' dealing with parental cancer demonstrate greater anxiety, depression and emotional distress than school age children (Huizinga, Visser, Zelders-Steyn, et al., 2011; Visser, et al., 2004). Furthermore, any existing tensions or strain in parent child relationships may be exacerbated by the cancer diagnosis (Turner et al., 2008). The normal developmental tasks as they relate to a parent's illness will influence adolescents' adjustment. Developmentally, adolescence creates fundamental changes in the family structure as youth strive for increased autonomy by withdrawing emotionally from their parents and striving for acceptance by their peers. Having a parent with cancer may require adolescents to adapt and negotiate normal developmental tasks which may need

to be placed on hold. This poses a significant threat to the adolescent's normal growth and development (Ohannessian, 2007).

Adolescents increased cognitive abilities and aptitude for abstract thought make them susceptible to distress because they are more knowledgeable about the potential future consequences of cancer than younger children (Spira & Kenemore, 2000). Furthermore compared to younger children, adolescents' greater cognitive and empathic capacities allow them to be more aware of losses and of the parent's physical and emotional pain (Christ, Siegel, & Sperber, 1994; Kristjanson, Chalmers, & Woodgate, 2004). Adolescents are also more able to accept additional household responsibilities which may detract from involvement in extracurricular activities with peers that support their positive development (Davey, Gulish, Askew, Godette, & Childs, 2005; Pedersen & Revenson, 2005; Sears & Sheppard, 2004; Spira & Kenemore, 2000; Stiffler, Haase, Hosei, & Barada, 2008).

In the case of advanced cancer, the family faces common stressors shared by all cancer diagnoses. Parents often focus their physical, emotional, and psychological resources on dealing with the demands of illness, however, in addition the family must deal with the uncertainties and emotional challenges an incurable diagnosis entails. The terminal phase of a parent's illness is a time of significantly higher psychological distress for family members than even the period following the actual loss (Siegel, Karus, & Raveis, 1996a). A prospective study of parental loss has also shown children who experience the anticipated loss of a parent are more likely to have psychological and

behavioral problems than children who experience the unanticipated loss of a parent (Saldinger, Cain, Kalter, & Lohnes, 1999). Moreover, several studies of cancer bereaved youth have shown significant long term consequences in this population including twice the risk of self injury compared to non-bereaved peers and higher levels of post-traumatic stress symptoms when compared to pediatric cancer survivors (Bylund Grenklo et al., 2013; Stoppelbein, Greening, & Elkin, 2006).

To date there has been extremely limited research on the adolescent's process of adjustment to advanced parental cancer. The limited studies that do exist examine adolescents impacted by parental cancer based on parent-report, there is a scarcity of data based studies that enable us to know the adolescents' experience from their own perspective. Currently, recommendations to parents and clinicians on how to talk or support adolescents dealing with advanced cancer of a parent lack any empirical basis in the medical, psychological, and nursing literatures (Muriel & Rauch, 2003 & Foley, Back, Coyle et al, 2005). There is a lack of evidence based interventions to help offset the stress of a cancer diagnosis on a family (Niemelä, Hakko, & Räsänen, 2010), in particular for families facing a terminal illness (Swick & Rauch, 2006). Development of psychosocial interventions should be based on empirical research; therefore there is a need for a synthesis of the current literature on families facing an advanced cancer diagnosis. A systematic and structured organization of this data would provide the understanding needed to progress psychosocial care for children and adolescents dealing with a parent's advanced cancer. Furthermore, once the specific factors associated with adolescents adjustment to advanced parental cancer have been identified, screening tools

and effective interventions for this population can be more readily developed (Krattenmacher et al., 2012).

This dissertation will provide a comprehensive examination of the effects of advanced parental cancer on adolescents. First this paper will provide a brief explanation of key concepts and terms used in the manuscript. Second, theories conceptually and empirically related to adolescent's adjustment to parental cancer will be presented. In addition a theoretical model will be presented as a guiding framework. This model is based on a prior systematic review of literature involving factors influencing children and adolescent's adjustment to parental cancer and was adapted from the resiliency model of family stress, adjustment, and adaptation and Su and Ryan-Wenger theoretical model (McCubbin, Thompson, & McCubbin, 1996; Su & Ryan-Wenger, 2007) Third, this paper will review the current state of empirical literature on the impact of a parent's advanced cancer on children and adolescents. Next, this paper will provide two studies examining the adolescents' experience of advanced parental cancer from the adolescents own perspective involving in depth qualitative interviews. Finally, this paper will discuss conclusions and clinical implications for future research consistent with the theoretical model presented.

Key Concepts

There are multiple concepts and terminology used in the literature on adolescents' adjustment to parental cancer that will be briefly described below in order to provide clarification for the purposes of this dissertation.

Risk and Resilience. Risk factors can be defined as characteristics in any child or adolescent's life that increase their vulnerability or likelihood they will experience negative developmental outcomes (Luthar, Cicchetti, & Becker, 2000). In simple terms, resilience can be defined as, "successful adaptation despite risk and adversity or ability to positively adapt to change" (Masten, Morison, Pelligrini, & Tellegen, 1994, p. 237). The American Psychological Association describes it as "the process of adapting well in the face of significant sources of stress" (n.d.). It can also be described as a dynamic process of positive adaptation that involves protective factors at the individual, familial, and contextual levels. In studying the resilience literature one realizes this is a complicated construct defined and measured in numerous ways; consequently, one must be cautious in the interpretation and generalization of findings from any given study. Resilience is clearly not a uni-dimensional domain. The main issues to consider when examining the multidimensional nature of resilience are as follows:

Resilience may not be a reflection of global adaptation across all domains thus high scores in one domain do not necessarily translate to high scores in another domain. Some findings may even indicate some high-risk children exhibit competence in some domains but exhibit problems in other areas. For example, a child who has a parent with cancer may continue to achieve academically in school but show signs of emotional distress at home.

Resilience is not a static state of being (Luthar, et al., 2000). All individuals show fluctuation over time within various adjustment domains. Luthar et al. (2000) states,

"individuals at high risk rarely maintain consistently positive adjustment over the long term" (p.11). Therefore just because individuals show high scores in one domain at one point in time this does not guarantee they will maintain high scores in that same domain over time. High risk individuals may be faced with new vulnerabilities or previously effective protective factors may no longer be present thus one must be critical in assessing long term resilience from a cross sectional design that may merely point to a resilient trajectory.

In conclusion, resilience can be described as an individual characteristic, the process an individual goes through, and the end result (Lee, Cheung, & Kwong, 2012). Resilience as a characteristic refers to an individual's capacity for adapting to change in a positive manner. Resilience as a process is the "reintegration process and return to normal functioning" after encountering a stressor (Lee, et al., 2012, p. 2). Resilience as the end result is described as the beneficial outcomes resulting from successfully adapting to stressful events. Thus, a complete definition of resilience must take into account all of these components (Lee, et al., 2012).

Protective and Promotive Factors. Protective factors were described by Kumpfer (1999), as "processes that are predictive of successful life adaptation in high-risk children (populations)." These protective factors offset risk, buffer or lessen risk and negative outcomes. Masten (1994) described them as "those attributes of persons, environments, situations, and events that appear to temper (mediate) predictions of pathology based upon an individual's at- risk status." (p.391) Some researchers argue

protective factors can only be meaningful in the presence of risk, therefore, Sameroff (1997), offered an improved phrase to describe the positive pole of a risk factor: promotive factors. These promotive factors can be found in both high risk and low risk populations and have direct main effects on positive outcomes or lessening of negative outcomes. This is in contrast to protective factors which have an interactive effect and actually lessen the risk factor itself. Promotive factors help with positive outcomes regardless of the risk factor (no risk factor is necessary), but they also do not actually offset the risk factor. The same variable can be a protective and promotive factor, but protective factors would generally have "no effect in low risk populations or be magnified in the presence of risk variables" (Gutman, Sameroff, & Eccles, 2002).

Variables that serve as a protective factor may not be consistent across all outcomes. O'Donnell's (2002) study of urban children exposed to various stressors found outcomes were independent and had different predictors depending on the level of risk factors. O'Donnell found positive support from parents and schools were positively associated with resilience in children exposed to a stressor and these associations increased as the child's level of exposure to the stressor increased. She found different types of support have different effects on children and the effects varied based on level of exposure to the stressor.

Post-Traumatic Stress and Post-Traumatic Growth. Posttraumatic stress is thought to be a result of the struggle to assimilate the disbelief of a traumatic event with one's own central belief system. The core beliefs of most people in Western cultures tend

to think of one's body as basically healthy, in one's own control, and invulnerable to death and disease (Tallman, Altmaier, & Garcia, 2007). Most people feel they are able to protect themselves from traumatic life events if they take the correct precautions. A cancer diagnosis seems to shatter these beliefs because people may have taken care of themselves and been a "good" person but still be diagnosed with cancer (Tallman, et al., 2007). Thus they may experience intrusive thoughts which resolve over time if the person is able to assimilate the trauma (Jim & Jacobsen, 2008). Post traumatic stress disorder (PTSD) is a result of a person not being able to resolve and integrate the traumatic experience and the "intrusive thoughts and avoidance become chronic" (Jim & Jacobsen, 2008).

Posttraumatic growth is when a person is able to not only assimilate and integrate the new information after the trauma but is also able to create meaning from the trauma and reframe it into a positive belief system (Tedeschi & Calhoun, 2004). Tedeschi & Calhoun (2004) define posttraumatic growth as the "positive psychologic change experienced as a result of the struggle with highly challenging life circumstances." In this way, a person is able to maintain their original belief system that they are in control, the body is basically good, and life is meaningful. This personal growth does not mean survivors do not experience trauma or distress but that they are able to maintain perspective and appreciate the negative and positive aspects of their disease (Tedeschi & Calhoun, 2004). In the literature on parental cancer, post traumatic growth has also been described as positive growth, stress related growth, and positive perspective; these terms

all encompass the idea that families have been able to appreciate and identify some positive outcomes of a cancer diagnosis.

Generalized Gratitude. Gratitude has been conceptualized as an emotion, an attitude, a personality trait, and a coping response. As a trait, gratitude refers not only to the gratitude that arises following help from others but also to a habitual focusing on and appreciation of the positive aspects of life. Thus, gratitude may be a more generalized orientation toward life independent of an exchange-based relationship (Emmons & McCullough, 2003). Generalized gratitude includes being grateful for that which is valuable and meaningful to oneself. A trait that involves a person's life orientation with a propensity to notice and appreciate the positive in life (Wood, Froh, & Geraghty, 2010). Research has shown gratitude is a key aspect to well-being and mental health. Recently, there has been an increase in the positive psychology literature of evidence showing how gratitude contributes to psychological and social well-being (Emmons & McCullough, 2003; Froh et al., 2011). The various characteristics of gratitude as outlined by Wood and colleagues (2008) include: "(1) individual differences in the experience of grateful affect, (2) appreciation of other people, (3) a focus on what the person has, (4) feelings of awe when encountering beauty, (4) behaviors to express gratitude, (5) focusing on the positive in the present moment, (6) appreciation rising from understanding life is short, (7) a focus on the positive in the present moment, and (8) positive social comparisons." Adult oncology researchers have begun to examine how gratitude in the general population is an important predictor of psychological well being and are making attempts to link and

utilize gratitude to address the needs of patients with life threatening cancer (Algoe & Stanton, 2012; Ruini & Vescovelli, 2012).

Theoretical Frameworks

Introduction

Cancer affects the psychological health and well-being of patients and their families (Weihs & Reiss, 1996). Moreover, the family's reaction to cancer and their ability to cope and be supportive has an effect on the illness outcomes as well (Mitschke, 2008). Increasingly, researchers and HCP's recognize cancer is a family experience, not only influencing the person with the diagnosis. This awareness grew from early theoretical papers by nurses, social scientists, and physicians (Barckley, 1980; Ervin, 1973; Lewis, Ellison, & Woods, 1985; Litman, 1974).

The theories that dominate a field exert a powerful influence by shaping how problems are perceived and defined and how potential solutions are framed (Hobfoll & Schumm, 2002). Historically, a handful of theories have accounted for the majority of theory based interventions in psychosocial support for children and adolescents dealing with illness. The most commonly applied theories found in the literature were chosen because they most closely related to our theoretical model of children and adolescents' adjustment to parental cancer. These include child/human development theories such as Erickson's Theory of Human Development and Piaget's Theory of Cognitive Development, and stress & coping theory. These theories and how they apply to our current level of care for adolescents dealing with a parent's cancer will be discussed.

Several theories relevant to this discussion are not individually discussed due to the scope and focus of the proposed framework developed for this dissertation. Grief & loss theory (Goldsworthy, 2005), attachment theory (Bowlby, 1990), health belief model (Gehlert & Browne, 2011), family systems theory (Morgaine, 2001; Titelman, 1998) were reviewed and pertinent concepts were integrated into the lens with which this topic was analyzed. Finally, family resiliency theory will be incorporated into this framework creating a conceptual model of family stress, adjustment, and adaptation to parental cancer (McCubbin & McCubbin, 1996).

Human Development Theories

Children and adolescents are more vulnerable to disturbances which threaten their mental equilibrium than are adults. The adolescent's stage of cognitive and emotional development often shapes their responses to illness and influences their ability to cope (Thompson & Stanford, 1981; Thompson, 2009). Age is an important determinant of the psychological, cognitive and emotional needs of adolescents. In addition, youth's developmental stage can affect the coping strategies utilized. The stresses put on the adolescent's life as a consequence of parental illness to a great extent are influenced by their stage of development. Consequently, an awareness of key developmental issues and how they interact with medical experiences is crucial for quality psychosocial care.

Erikson's theory of human development. Erikson believed personality progresses in a sequence of stages. His theory of human development illustrates the effect of social experience across a person's lifespan. The development of ego identity is a core

construct in this theory. Erikson believed a person's ego identity continually shifts due to new experience and information we attain in our day to day interactions with others. His theory outlined how the motivation behind our actions stemmed from a sense of competence. Every stage is concerned with gaining competence in an area of life. If the stage is dealt with properly, the person will feel a sense of mastery. If the stage is handled unsuccessfully, the person will surface with a sense of inadequacy (Erikson, 1963; Erikson, 1994).

Application to impact of illness on adolescent development. In view of Erickson's stages, the impact of illness on an adolescent's development can be profound. For example, in this stage of Identity versus Role Confusion adolescents are beginning to form their own identity and developing independence. An unexpected illness in the family can create an extreme sense a loss of normalcy, shame about ill parent (due to need for peer acceptance) and ambivalence about their desire for autonomy. As a result, rather than completing this stage by the adolescent establishing a strong independent identity, they may instead be left with a sense of guilt for wanting to separate from the ill parent leading to negligence or compromise of their own growth and autonomy. In addition, a parent with cancer may have symptoms such as fatigue, mood swings, and lack of energy that lead to increased care giving responsibilities for the adolescent that interfere with peer activities and school work. Some adolescents identify so closely with the ill parent that they begin to have concerns for their own health and body. Table 1.1 outlines Erikson's Psycho-social stages and how they may be impacted by illness.

Stage	Age	Crisis	Tasks	Impact of Illness/Psychological Issues
Infancy	Birth to 2 yrs	Trust vs. mistrust	Attachment, emotional development, sensorimotor development	Disrupted attachment to primary caregivers; inconsistent physical and emotional care by parents
Toddlerhood	2-3 yrs	Autonomy vs. shame & Doubt	Language, fantasy play, control	Sense of loss of control; separation from parents (experienced as abandonment or punishment); Inconsistent provision of attention and limit setting
Early School Age	4-6 yrs	Initiative vs. guilt	Gender identification, moral development, self-theory, peer relationships	Fantasy/magical and ego-centric thoughts lead to feelings of guilt that they have caused the illness; fun and play perceived as inappropriate
Middle childhood "Latency"	6-12 yrs	Industry vs. inferiority	Friendship, concrete operations, skill learning, self-evaluation	Irrational fear of causing or exacerbating the parent's illness and associated guilt; guilt for having fun; feeling unimportant; need to feel they have a role in helping with ill parent; somatic complaints (due to identification with ill parent); fear of losing healthy parent (due to age expected dependency on parents)
Adolescence	12-18 yrs	Identity vs. confusion	Physical maturation, formal operations, emotional development, peer group membership, romantic relationships	Sense a loss of peer acceptance and sense of normalcy; shame about ill parent (due to need for peer acceptance); guilt or ambivalence about desire for independence (due to age expected need for autonomy); somatic complaints due to concerns about body image and healthy identity formation issues; resentment of increased responsibilities at home; negligence or compromise of own growth and autonomy (due to guilt for wanting to separate form ill parent)

Table 1.1 Erikson's Psychosocial Stages of Development

Piaget's theory of cognitive development. Piaget's stages of cognitive development illustrate that children and adolescent's logic in regards to space, time, and causality is fundamentally different from adults. Their logic "not only relies on different principles, but also follows a developmental sequence" (Thompson & Stanford, 1981, p. 69). Piaget was interested in how an individual adapts to its environment. Conduct or adaptation to the environment is controlled through intellectual organizations called schemes the individual uses to represent the world and label action. A biological urge to achieve balance between schemes and the environment causes this adaptation to occur. This is known as equilibration.

Piaget depicts two processes used by people in their attempt to adapt: assimilation and accommodation. People progressively adapt to the environment using these processes in increasingly complex manner. "Assimilation is the process of using or transforming the environment so that it can be placed in preexisting cognitive structures. Accommodation is the process of changing cognitive structures in order to accept something from the environment. Both processes are used simultaneously and alternately throughout life." (Ginsburg & Opper, 1988, p. 188)

Application to impact of illness on adolescents' development. Piaget's theory provides HCP's with an outline of an adolescent's general beliefs about illness and predicts the way in which these beliefs are altered over time. Therefore, allowing HCP's to recognize the manner in which they assimilate their experience of illness related to the stages of their cognitive development (Biba ce & Walsh, 1980). This can guide

explanations of illness for adolescents, and helps HCP's to create appropriate educational opportunities. Focusing on Piaget's formal-operational stage of development (ages 12- 18 yrs) the major developmental milestone is their acquisition of deductive reasoning and conceptual thinking skills (Piaget, 1952). As adolescents have the capability for abstract thought, they are able to grasp concepts such as the causes of the illness, disease progression, the chronic nature of some cancers and the possibility of death. They understand symptoms such as fatigue are due to illness and treatment but this may not assuage negative emotions they may have toward the parent due to the changes caused by the cancer. As a consequence they may feel remorseful or guilty about such negative feelings. Their greater understanding of the ramifications of the illness may also instigate concerns about their own health and risk for developing cancer. Table 1.2 outlines Piaget's Stages of Cognitive Development and how they influence children and adolescent's perception of illness.

A limitation to relying heavily on developmental theories and stages may be that many children and adolescents do not fit perfectly into a particular stage and one must assess the individual adolescent's level of understanding and issues with the illness without making broad assumptions merely based on their developmental age.

Stage	Age	Description of Stage	Developmental Phenomenon	Perception of Illness
Sensorimotor stage	Birth to 2 yrs	Experiencing the world through sense and actions	Stranger anxiety Object permanence	Separation from caregivers; physical pain
Pre-operational stage	2-6 yrs	Representing things with words and images	Egocentric thought Language Development Pretend play	Fantasy of reason for illness; link ill parents condition with their own behavior; feel they caused illness; Illness experienced as punishment
Concrete operational stage	7-11 yrs	Thinking logically about concrete events and Grasping concrete analogies	Conservation; separation of self from others	Concrete understanding of world leads to misconceptions about illness; define illness through observable behavior such as lying in bed; Fear of contamination
Formal operational stage	12-18 yrs	Thinking about hypothetical scenarios and grasping abstract thought	Abstract logic; moral reasoning	Understand long term implications of illness on family; may be preoccupied with fear of potential genetic transmission of parent's illness to themselves; consciously reflect on how to reduce burden for parent

Table 1.2 Piaget's Stages of Cognitive Development.

Stress & Coping Theory

Much of the literature on children and health care is shaped by the constructs of stress and coping. Coping literature was preceded by stress research, which examined the varied stressful encounters experienced by individuals and the eventual effects of the stress of these encounters on the health and well-being of the individual (Mitschke, 2008). Stress refers to an ongoing transaction between a person and the environment resulting in an emotional appraisal that the situation is threatening or harmful to some aspect of well-being. In "stressful" situations people usually feel little or no control over the situation, or feel unable to change the situation in order to remove the threat or harm (Gaynard et al., 1990). Richard Lazarus (1985) and his colleagues developed a theory of psychological stress and coping. They note stress is a very subjective matter and there are two aspects to psychological stress: the event or stimulus that causes the stress and an individual's response to that stressor. The response or "appraisal" process consists of the initial judgment of whether the threat exists and the secondary appraisal of how that person can cope with the threat. Lazarus & Folkman (1984) have suggested the coping process consist of four steps. The first step is appraisal, which involves determining the meaning of an event or situation and it's implications for one's well-being. The second step involves assessing one's coping resources and the likelihood various coping strategies will be effective, culminating in the selection of a coping strategy. The third step involves carrying out the selected coping strategy. Finally, the fourth step involves evaluating one's coping effort with regard to their effectiveness in eliminating or reducing the stressor or managing one's response to the stressful event.

In 2000, Lazarus began to move toward a model of coping process rather than the stress process. Coping refers to what a person does in order to "avoid, remove, or minimize a stressful situation" (Lazarus, 1993). Coping efforts can be "problem-focused", trying to change something in the environment or "emotion-focused", trying to deal with the thoughts and feelings related to the stressor (Gaynard, et al., 1990). Problem focused coping can mediate the emotional distress of a stressful experience (Lazarus, 2000). Moreover, when stressful conditions are seen as unalterable then emotion focused coping strategies are most beneficial. Folkman and Lazarus (1988) also emphasize the relationship between emotion and coping as mutually reciprocal. Effective coping is also described in the developmental theories. They assert that when children and adolescents are able to cope successfully with stressful events related to an illness in the family they obtain a sense of self efficacy and mastery that is then generalized to other potentially stressful encounters. Consequently, the illness experience has the potential to create positive growth and development. The coping theory provides a framework that focuses on positive aspects, qualities, and abilities inherent in an individual. This closely aligns with the social work profession's belief that empowering people by building on their strengths is vital to their success.

Although stress and coping theory is essential in understanding what happens to the adjustment of individuals, they do not sufficiently address the complexity of issues that occur in families affected by cancer (Wenzel, Glanz, & Lerman, 2002). It is clear stress related variables are components of complex transactions among genetic, psychological, and environmental factors that affect how a person copes (Rice, 2000).

The importance of these variables lies in the possibility that they play a role in making a person resistant or vulnerable to stress experiences. Values, beliefs and general attitudes affect the meaning a person derives from a given situation. As explained by Lazarus (1984), the appraisal of threat triggers a secondary appraisal that not only influences what stress emotion is experienced but also influences what determines coping responses. Lazarus (2000) also emphasizes the role values, goals, beliefs, and personal resources play not only in influencing primary appraisal but also in determining the particular emotion experienced through secondary appraisal that connects the relational meaning of the situation to how the person feels and acts. Attitudes, beliefs, values, and culture are antecedent factors for understanding behaviors and are among those variables that are very important for coping. Consequently, we can make the assumption that cultures have unique values, beliefs, and attitudes that define stressful experiences (Rice, 2000).

Examining the research paradigms of coping and stress reveals they do not adequately illuminate the experiences of some populations (Mitschke, 2008). Coping is treated as an abstract concept untouched by such individualizing characteristics as gender, race or class (Banyard & Graham-Bermann, 1993). Often value judgments are placed on coping strategies and the dichotomy created between positive and negative coping is problematic for some minority populations. Stress and coping theory is limited by its general assumptions about people's experiences and how they influence their coping.

The literature on coping theory and specifically, coping with illness has grown exponentially over the last 40 years (Livneh & Martz, 2007). One reason for this may be that many illnesses such as cancer that used to be thought of as terminal have been gradually transformed into chronic illnesses with higher rates of prolonged lives. With the increase in life lengthening treatments, the interest in the psychosocial consequences of these conditions has grown. As more people are surviving cancer, the focus in social work practice and research has shifted from helping families to deal with bereavement and loss, to framing cancer as a chronic illness or a permanent stressor in which families learn to cope and alter functioning to accommodate survival (Mitschke, 2008).

Family Resiliency Theory

Family resiliency theory highlights the complex but meaningful role which family resources, behaviors, and capabilities play in buffering the impact of stressful life events and facilitating the family's recovery in the face of family crisis such as a serious illness (McCubbin & McCubbin, 1993, 1996). A cyclical model of family resilience developed by McCubbin and McCubbin (1996) aims to explain why, in similar circumstances, some families fall apart and others thrive. This model, the resiliency model of family stress, adjustment and adaptation (McCubbin & McCubbin, 1996), is based on four models, the first being Reuben Hill's ABCX model, proposed in 1949. Two phases occurring over time are depicted in the model: adjustment phase and adaptation phase after experiencing a stressful life event. In the adjustment phase, the family relies on established patterns of family functioning, resources, appraisal, coping strategies, and problem solving with only

minor changes being made. If this reliance is not adequate to manage the situation, the family is seen as being in crisis, and this marks the beginning of the adaptation phase. Protective factors buffer individuals from a stressor, operate over time, and influence processes and interpersonal reactions both directly and indirectly (Hawley & DeHaan, 1996). Recovery factors, on the other hand, help a family to restore effective family functioning after a crisis period (McCubbin, Thompson, & McCubbin, 1996). Protective and recovery factors may be referred to collectively as resilience factors.

In this model resiliency was defined as "the positive behavioral patterns and functional competencies individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family's ability to recover by maintaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and the family unit as a whole" (McCubbin & McCubbin, 1996, p. 5).

Model assumptions include the following: (a) families experience stress and hardship as a predictable aspect of family life over the life cycle; (b) families also possess strengths and develop competencies to protect and assist in the recovery from both expected and unexpected non-normative stressors and strains and to foster the family's recovery following a family crisis; (c) families benefit from and contribute to a network of relationships in the community, particularly during periods of family stress and crisis; (d) families will search for and establish a view that will give the family meaning, purpose, and shared perspective so the family can move forward as a group; and (e) families faced with major stressors and crises seek to restore order, balance, and harmony

even in the midst of great upheaval. Thus, the process of restoration and adaptation involves changes within family relationships as well as relationships with the broader community to reestablish individual and family well-being (McCubbin & McCubbin, 1996).

As used in this model, crisis is not a negative term. Instead, it refers to the family experience of a state of disorganization and the need for change. Consequently this model is well suited as a foundation for a theoretical framework for children and adolescent's adjustment to parental cancer. Given that even high functioning families experience crises such as cancer, a theoretical framework needs to take into account the fact that the distress experienced by children and families facing cancer is normative, not pathological and has the potential to be buffered by resilience factors.

It has been well documented that the diagnosis of cancer in a parent puts the family into crisis (Lewis, 2007; Lewis, 1985). Therefore, these families move quickly into the adaptation phase. In adaptation, the accumulation of family demands due to the parent's illness and from all areas of work and family life are considered and depicted as increasing the family's exposure to stress. Strengths and capabilities or resiliency factors during the adaptation phase include newly established patterns of family functioning; acquiring new or activating old social support resources at the individual, family, and community levels; and actively engaging in new coping and problem-solving strategies. Changes in appraisal also occur and existing family beliefs, goals, and values are challenged.

The Resiliency Model of Family Stress, Adjustment, and Adaptation, a stress and coping framework based on a family systems approach, is useful for describing a family's response to parental cancer. In this paper, this resiliency model is adapted to create a theoretical framework used to examine the factors potentially affecting an adolescent's adaptation to having a parent diagnosed with cancer. (See Figure 1.1)

Conclusion

The ultimate goal of theory and research in a practice discipline such as social work is development of effective interventions. To achieve this, social work interventions should be derived from theory, research, and clinical observations. A theoretical model is a useful way to illustrate how important concepts interrelate. Lewis and her colleagues (1989; 1993) presented an explanatory model to explain family functioning when a mother has cancer or a chronic illness. This model focuses on the whole family functioning rather than simply children's adjustment. The relationships between the variables are complex. The following theoretical model (Figure 1.1) proposes a framework that illustrates the interrelationships among adolescent and family characteristics, family functioning and relationships, and child and adolescent well-being. A systematic review of existing literature provided the foundation for this framework incorporating theoretical, clinical, and empirical work on families coping with parental cancer, particularly research grounded in family systems and developmental perspectives.

According to McCubbin and Patterson (1982), adjustment represents a short-term response, adaptation implies long-term consequences. Based on Hoke's (2001)

classification (four types of children's reactions to a parent's cancer), adjustment is defined as the degree to which a child or adolescent is functioning in terms of emotional/mood, somatic, as well as social and interpersonal dimensions. Accordingly, in this model maladjustment suggests the adolescent demonstrates more bio-psychosocial problems than the average population. Bonadjustment suggests that adolescents who have a parent with cancer have fewer than or the same level of bio-psychosocial problems as the average population. The theoretical model proposed below strives to conceptualize cancer as a family's experience and emphasizes the need to address the potential impact it may have on children and adolescent's adjustment. Figure 1.1 (please see attached)

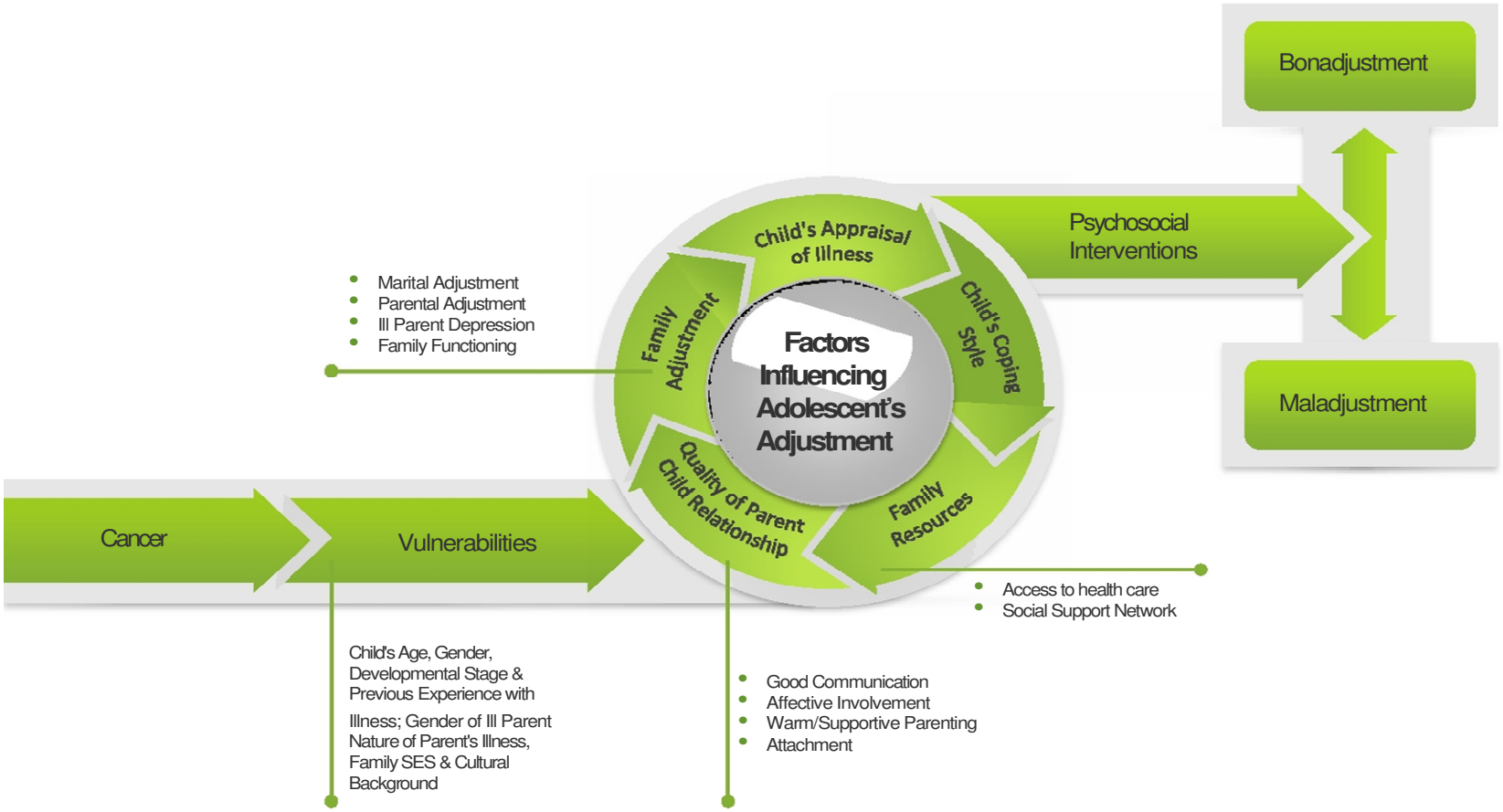

Figure 1.1 Model of Factors Influencing Children & Adolescent's Adjustment to Parental Cancer
(Adapted from the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996))

Methodology

Inductive Content Analysis. Inductive content analysis was used to develop an explanatory theory of the adolescent's experience with advanced parental cancer. Inductive content analysis is well-suited for conducting research where minimal previous studies of the phenomenon exist. The inductive approach allows researchers to identify key themes in the data by reducing the material to a set of discrete units. Then using inductive reasoning domains and categories emerge from the raw data through repeated examination and comparison. The inductive coding methods used were adapted from methods originally described by Glaser and Strauss (1967) and later extended by Lewis and Deal (1995). Analysis began with the bracketing of the first author's assumptions about adolescents dealing with a parent's advanced cancer before transcripts were read several times in their entirety in order to understand the meaning of the data as a whole (Moustakas, 1994). The goal of this naïve reading was to grasp a pre-understanding of the first author's preconceptions about the subject matter before interpretation began (Grbich, 2007). Initial interpretation of the transcribed data consisted of identifying the units of analysis. The unit of analysis was coded as a complete idea, not a complete sentence. Therefore, compound sentences were coded as multiple units (Lewis & Deal, 1995). Upon completion of establishing the units of analysis the open coding process began. Open codes were analyzed, compared, and categorized on the basis of the manifest meaning of the text (Houldin & Lewis, 2006; Lewis & Deal, 1995). The categories consisted of coded units that had common elements and when possible categories were labeled with emic rather than etic titles using the

participants own words (Lewis & Deal, 1995; Strauss & Corbin, 1994). Constant comparative analysis was performed once categories were identified in order to obtain best fit of each unit within a category, maximum consistency of grouped units, and to validate uniqueness of each category avoiding redundancy (Lewis & Deal, 1995; Strauss & Corbin, 1994). During the coding process the definitions of categories were formed and continually refined in order to maximize distinction across categories. The coder and authors worked to obtain consensus among the categories chosen and their definitions. This consensus was achieved through discussions resulting in refined category definitions, distinguishing new categories, or moving units of analysis into different categories. Finally, the categories were further organized into larger groupings or domains that led to the development of a core category (Lewis & Deal, 1995).

Phenomenology. Phenomenology is well suited for the examination of understudied populations because it provides rich text and deep meaning of lived experiences though the participants own words and descriptions (Creswell, 2007). Phenomenological analysis was used to facilitate an understanding of the essential meaning of lived experiences from the adolescents' perspective. The common themes and shared experiences of the adolescents' interviewed were the focus of the study.

The data for the study were face to face in depth interview with adolescents living with a parent with advanced cancer in Austin, Texas. The interviews were completed between October of 2012 and April 2013. A phenomenological analysis of the text was completed following the final data collection and transcription of interviews. The researcher used a combination of the various approaches to phenomenological analysis as

described by Moustakas (1994). Organization of data began when the researcher carried out a naïve reading and studied the entirety of the data including all transcribed interviews. However, the researcher's position as a clinician involved with this population and agency cannot be ignored and was addressed through adhering to the phenomenological procedures of writing assumption statements, bracketing, writing field notes throughout the analysis process, and peer review. Prior to performing the interviews the researcher recorded a list of assumptions about the population being studied in an effort to address the research with a "fresh perspective" (Creswell, 2007). Analysis began by listing every expression relevant to the cancer experience (Moustakas, 1994). As the researcher gained an overview of the participants' experience, the data was reduced by listing all statements and eliminating those that were repetitive, vague or overlapping. This process allows the researcher to obtain the meaning units or invariant constituents (Moustakas, 1994). These meaning units were then clustered or categorized into themes. The researcher uncovered common threads or concepts that linked participant experiences together in order to create these themes which were again reduced by removing overlapping or repetitive statements. The themes were validated by checking them against the complete transcriptions, making sure they were either explicitly expressed or compatible. The reliability of the themes were assessed through peer checking using a panel of experts on qualitative methods (Padgett, 1998; Rolfe, 2006). In hermeneutic phenomenology, validity refers to the fact there are no internal contradictions within the study (Armour, Rivaux, & Bell, 2009). From the ten verbatim transcripts, significant statements were extracted. Table 4.2 includes selected examples

of these statements and their formulated meaning units. Arranging these meaning units into clusters resulted in the 4 basic themes. Table 4.3 contains two examples of theme clusters that emerged from their meaning units. These validated themes were labeled as the core of the experience and were used to develop textural descriptions. The textural descriptions are considered "what" the participants experienced with the phenomena and include verbatim examples from the transcribed interviews (Creswell, 2007). Next, the structural descriptions or "how" the experience happened was formed by reflecting on the setting and context in which the phenomena was experienced (Creswell, 2007). Finally, from the integration of the textural and structural descriptions into the meanings and themes of the experience the essence of the phenomena was constructed. This final synthesizing of the data and creation of a composite description of the lived experience for the group as a whole was the ultimate goal of this phenomenological study.

Research Questions and Components of Three-Article Dissertation

Article One

RQ1: How does advanced parental cancer impact children and adolescents?: A review of the literature.

Abstract

Families and children facing the death of a parent from cancer constitute a vulnerable population often overlooked by health care professionals (HCP) and researchers. The purpose of this review is to provide a systematic analysis of the literature that examines the experiences of parents diagnosed with advanced cancer and their adolescent children. Review of quantitative, qualitative, and mixed method publications between 2000 and 2013 were selected in order to obtain the most current and timely studies. Articles

published before 2000 but found to be seminal works on this topic were also included. No time limits were set on intervention studies. Seventeen studies met the criteria for the content of this review, indicating the limited number of studies conducted on this topic. Articles were summarized using the following categories: original research on the impact on the family and parenting; original research on the impact on the child/adolescent; interventions for families facing incurable cancer. The analysis was organized around the major themes found in the literature within each category. These themes will allow HCP's to understand implications for clinical practice and apply the knowledge gained from this analysis of literature to guide future research.

Targeted Journal: *Psycho-Oncology*

Article Two

RQ2: Understanding the experiences of adolescents and applying their own words to develop an explanatory theory of their experiences with advanced parental cancer.

Abstract

Parental cancer is a stressful experience for young people, constituting a potential threat to physical and mental health, and normative development. Currently, there is insufficient information describing the nature of this distress when a parent has advanced cancer, especially concerning families with adolescent children. The aim of this study is to address the significant gap in the literature offering the adolescent's perspective regarding the impact of their parent's advanced cancer on their lives. This qualitative study involved single occasion, semi-structured interviews with adolescents whose parents were diagnosed with advanced stage cancer. In addition, standardized questionnaires of adolescent psychological functioning were completed. The study

sample consisted of seven adolescents, five female and two male ranging in age from 11-15 years (M=13.6, SD=1.4). The core construct that organized study results was weaving a normal life with cancer. Weaving a normal life with cancer involved five major domains: *feeling the weight of the world on my shoulders, cancer changes everything, strategies-I don't like middle ground, either directly confronting it or going away, talking about it, cancer was a positive for me…it taught me.* Our findings shed light on how families managed when the "terminal phase" of cancer stretched on for many years. Implications for HCP's include the need to facilitate family interventions that provide parents and adolescents with a venue to communicate and process the impact of cancer on their lives. This may allow for opportunities to reframe the cancer experience and find positive meaning from their challenges.

Note: The data collection for this article was completed by Dr. Frances M. Lewis and her research team at the University of Washington. My role as first author was data analysis, interpretation of results and writing of the manuscript.

Targeted Journal*: Palliative Medicine*

Article Three

RQ3: What is the lived experience of adolescents living with a parent with advanced cancer?

Abstract

Adolescents are considered to be the group most susceptible to negative psychosocial outcomes when faced with a parent's illness. Yet, there has been extremely limited research on the adolescent's adjustment to advanced parental cancer. The aim of this study was to gain understanding of the experiences of these adolescents in their own

words to gather pilot data on the needs of this population that will be valuable in developing interventions for adolescents facing parental cancer. A hermeneutic phenomenological approach was applied using in-depth, semi structured interview methodologies to inquire about the adolescents experiences. Ten adolescents (7 males, 3 females) aged 14- 17 were interviewed. Four essential themes about adolescents living with a parent's advanced cancer emerged from the analysis: *Life interrupted, Being there, Managing emotions, Positives prevail.* The findings in this study underscore the significant impact an advanced cancer diagnosis can make on a family system and suggest the experience may also have the potential of creating opportunities for growth and well being. Our findings reinforce previous results that advocate the importance of family and peer support, positive attitude, and open communication when a family is coping with advanced parental cancer. Understanding how adolescents gain strength from their relationships with family and peers offers healthcare professionals an opportunity to have services and strategies in place to foster these relationships.

Targeted Journal: *Journal of Social Work in Palliative and End of Life Care*

Chapter 2

Adolescents living with a parent with advanced cancer: A review of the literature

Abstract

Families and children facing the death of a parent from cancer constitute a vulnerable population often overlooked by health care professionals (HCP) and researchers. The purpose of this review is to provide a systematic analysis of the literature that examines the experiences of parents diagnosed with advanced cancer and their adolescent children. Review of quantitative, qualitative, and mixed method publications between 2000 and 2013 were selected in order to obtain the most current and timely studies. Articles published before 2000 but found to be seminal works on this topic were also included. No time limits were set on intervention studies. Seventeen studies met the criteria for the content of this review, indicating the limited number of studies conducted on this topic. Articles were summarized using the following categories: original research on the impact on the family and parenting; original research on the impact on the child/adolescent; interventions for families facing incurable cancer. The analysis was organized around the major themes found in the literature within each category. These themes will allow HCP's to understand implications for clinical practice and apply the knowledge gained from this analysis of literature to guide future research.

Cancer is the second leading cause of death in the United States and is responsible for approximately 1 of every 4 deaths (ACS, 2011). These statistics along with the fact that close to 25% of cancer cases occur in individuals 21-55 years of age, prime child-

bearing and parenting years, highlight the importance of creating resources for family's dealing with a cancer diagnosis (Horner, Ries, & Krapcho, 2009). Furthermore, it is estimated that close to 55,000 children may experience the death of a parent from cancer each year in the United States (Weaver, et al., 2010). Families and children facing the death of a parent from cancer constitute a vulnerable population often overlooked by health care professionals (HCP) and researchers.

The diagnosis of cancer in a parent triggers psychological and social pressure in children. Research has shown children and adolescents are severely impacted by a parent's cancer diagnosis in all domains of child functioning, in particular emotional well being (Visser, et al., 2004). As cancer becomes more of a chronic issue due to advances in cancer treatment, children and adolescents are potentially dealing with the long term consequences of this disease for a substantial portion of their childhood (Osborn, 2007). The continuous threat of a parent's cancer recurring, or the threat of death of their parent, may cause long term negative psychosocial outcomes for children and adolescents (Huizinga, Visser, Zelders-Steyn, et al., 2011).

Adolescents have been the most negatively affected group when faced with a parent's illness. Findings suggest adolescents' dealing with parental cancer demonstrate greater anxiety, depression and emotional distress than school age children (Huizinga, Visser, Zelders-Steyn, et al., 2011; Visser, et al., 2004). Developmentally, adolescence creates fundamental changes in the family structure as youth strive for increased autonomy. Having a parent with cancer may require typical developmental tasks to be

placed on hold thus posing a significant threat to the adolescent's normal growth and development (Ohannessian, 2007). Their increased cognitive abilities and aptitude for abstract thought make them susceptible to distress because they are more knowledgeable about the potential future consequences of cancer than younger children (Spira & Kenemore, 2000). Furthermore, adolescents' increased cognitive and empathic capacities enable them to be more conscious of losses and of the parent's physical and emotional pain (Christ, et al., 1994; Kristjanson, et al., 2004). Adolescents are also more able to accept additional household responsibilities which may detract from involvement in extracurricular activities with peers that support their positive development (Davey, et al., 2005; Pedersen & Revenson, 2005; Sears & Sheppard, 2004; Spira & Kenemore, 2000; Stiffler, et al., 2008)

In the case of advanced cancer, the family faces common stressors shared by all cancer diagnoses. Parents often focus their physical, emotional, and psychological resources on dealing with the demands of illness, however, in addition the family must deal with the uncertainties and emotional challenges an incurable diagnosis entails. The terminal phase of a parent's illness is a time of significantly higher psychological distress for family members than even the period following the actual loss (Siegel, et al., 1996a). Moreover, several studies of cancer bereaved youth have shown significant long term consequences in this population including twice the risk of self injury compared to non-bereaved peers and higher levels of post-traumatic stress symptoms when compared to pediatric cancer survivors (Bylund Grenklo, et al., 2013; Stoppelbein, et al., 2006).

It is important for clinicians and researchers to understand the needs of this understudied population. The purpose of this review is to provide an analysis of the literature that examines the experiences of parents diagnosed with advanced cancer and their adolescent children.

Method

Search Strategy

The search strategy surveyed a range of electronic bibliographic databases including the Cumulative Index to Nursing and Allied Health literature (CINAHL), PsychINFO, PubMed, ISI Web of Knowledge, Google Scholar and MEDLINE. The search terms used were *parental cancer, advanced cancer, metastatic, advanced stage, recurring cancer, parental terminal illness, maternal terminal illness, paternal illness, cancer, neoplasm*, coping, adjustment, adolescent, and teen**. These key words were utilized in various combinations to narrow the search to the content of the specific topic. The search was also limited to publications written in English published in peer-reviewed journals. Review of quantitative, qualitative, and mixed method publications between 2000 and 2013 were selected in order to obtain the most current and timely studies. Articles published before 2000 but found to be seminal works on this topic were also included. No time limits were set on intervention studies. Reference lists of relevant publications were also examined.

Inclusion Criteria

The articles selected for review met the following criteria: (1) the population of interest included adolescents exposed to parents with advanced cancer; (2) advanced cancer was defined as: incurable, terminal, Stage IV, or metastatic disease; (3) psychosocial issues for the children, adolescents aged 12-18 and/or parenting issues were key outcome measures; (4) intervention studies used some method of analysis to evaluate the intervention's outcomes. Studies were excluded if data for families with advanced cancer were aggregated with other stages of disease and main results could not be derived specific to the target population. Studies were also excluded if the main outcome measures focused solely on the adjustment of patient or spouse without reference to the child/adolescent, and if the sample/outcome measure was bereavement rather than issues related to adjustment pre-death. Studies were not required to meet a quality threshold due to concerns about presenting an overly restricted picture of this modest research area. Due to the lack of quantitative methods used in the included studies, a meta-analysis was considered inappropriate and a structured narrative approach has been taken.

Results

Seventeen studies met the criteria for the content of this review, indicating the limited number of studies conducted on this topic. Thirteen studies were published within the last 10 years, 2003-2012. Nursing, psychology, medical, and social science practitioners and researchers from the United States (7), Canada (3), Australia (3), Norway (2), and the United Kingdom (2) comprised the investigative teams. The

majority of studies were cross sectional (14) and/or qualitative (12). There were four quantitative studies with inclusion of a comparison group (Rainville, Dumont, Simard, & Savard, 2012; Siegel, et al., 1996a; Siegel, et al., 1992; Sigal, Perry, Robbins, Gagne, & Nassif, 2003); one mixed method study (Turner, Kelly, Swanson, Allison, & Wetzig, 2005); and two longitudinal in design (Bell & Ristovski-Slijepcevic, 2011; Siegel, Karus, & Raveis, 1996b). Only three of the studies exclusively examined the adolescents' experience (Christ, et al., 1994; Rainville, et al., 2012; Sheehan & Draucker, 2011). Most studies examined mixed advanced cancer diagnosis with two studies examining only parents with breast cancer (Turner, et al., 2007; Turner, et al., 2005) and one focused on patients diagnosed with colorectal cancer (Houldin & Lewis, 2006). Sample sizes ranged from six to one hundred and twenty participants. Eleven studies used some type of outcome measure for the children/adolescents and only four intervention studies were found that focused on parental advanced cancer. Articles were summarized in tables using the following categories:

1. Original research on the impact on the family and parenting- 6 articles (Table 2.1)
2. Original research on the impact on the child/adolescent- 7 articles (Table 2.2)
3. Interventions- 4 articles (Table 2.3)

The analysis was organized around the major themes found in the literature within each category. These themes emerged by reviewing the most common themes found in the collected literature and building on the researcher's conceptual model of factors influencing adolescent's adjustment to parental cancer.

Impact on the Family and Parenting

Need to maintain normalcy. Parents worked hard to maintain normalcy in their family's lives, especially their children's social activities (Bell & Ristovski-Slijepcevic, 2011; Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; Turner, et al., 2007; Turner, et al., 2005). Yet, severe fatigue and side effects from cancer treatments were described as impediments to maintaining stability, normalcy and daily routines (Bell & Ristovski-Slijepcevic, 2011; Houldin & Lewis, 2006). Mothers in particular described a sense of responsibility to their children to maintain normal household routines despite their side effects (Bell & Ristovski-Slijepcevic, 2011). Women felt keeping a routine and structure in their children's lives would make children feel safe and grounded (Turner, et al., 2007). Some parents believed successfully maintaining normalcy and not communicating about the illness would protect their children from the emotional impact of cancer (Kennedy & Lloyd-Williams, 2009).

Parenting became a priority. The sicker parents became the more parenting became a chief concern in their lives (Sigal, et al., 2003). As one woman shared "I used to want a lot of things. Now, all I want is to see my children grow up" (Bell & Ristovski-Slijepcevic, 2011, p. 633). Whether parents attempted to be better listeners, spend more time with their children, or create memories to sustain long-term attachment, parents with an advanced cancer diagnosis felt compelled to be good parents. Sigal et al. (2003) examined the mother child relationship between women with early stage breast cancer versus metastasized breast cancer with surprising results. They found the sicker mothers

and their children were coping better with the illness with reports of less poor parenting and fewer behavioral problems in their children (Sigal, et al., 2003). The authors suggested this was due to the fact that once the mothers realize they may die they begin maximizing the time they have left with their children. Moreover once the children comprehend the seriousness of their parent's condition they may attempt to protect their parents by controlling any disruptive behavior. They concluded parents with advanced cancer recognize the life limiting nature of their illness and in turn make parenting and their relationship with their children a priority in their lives (Sigal, et al., 2003).

This idea was also supported by the qualitative studies. Houldin and Lewis (2006) interviewed fourteen patients with Stage IV colorectal cancer. Parents shared how they were forced to "rethink their parenting" by not only trying to spend more time with their children but even "listening to them more" (Houldin and Lewis, 2006, p722). Sheehan & Draucker (2011) attempted to create an explanatory model outlining interaction patterns between parents with advanced cancer and their adolescent children. Using a constructionist grounded theory approach, analysis of their data revealed the core variable as Making the Most of the Time We Have Left Together. The study's explanatory model depicts the adolescents and ill parents' responses to the realization their time together was limited by the parent's impending death. Ultimately, parenting their adolescent well was a critical concern even for the very ill parent. Their model reflects a dynamic process by which families continuously adjust their relationships in the face of advanced cancer. O'Callaghan and colleagues (2009) analyzed the lyrics of songs written by parents with metastatic cancer to their children. They found parents used these

songs as a way to facilitate their child's sense of connectedness to the hospitalized parent and as a way to ensure ongoing attachment to them after death (O'Callaghan, et al., 2009)

Drawing on ethnographic fieldwork at a support group for women with metastatic cancer, Bell & Ristovski-Slijepcevic (2011) explored the relationship between mothering and living with advanced cancer. Mothering for these women became 'a race against time' as they attempted to 'cram a lifetime worth of parenting into a few short years' by making every effort to create memories (Bell & Ristovski-Slijepcevic, 2011).

Talking with children about advanced cancer. Parents expressed concerns about ways to talk with their children about their advanced cancer (Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; Turner, et al., 2007; Turner, et al., 2005). Communication is an important factor to help children adjust to parental cancer. Yet, parents struggled with the amount of information, timing and language used to explain advanced disease (Houldin & Lewis, 2006; Turner, et al., 2007; Turner, et al., 2005). Mothers wondered if children would understand the implications of metastatic disease (Turner, et al., 2005) and also felt the need to maintain hope while still being honest with their children (Turner, et al., 2007).

The consensus was that parents did not receive guidance or support from health care professionals on how to talk to their children about advanced cancer (Kennedy & Lloyd-Williams, 2009; Turner, et al., 2007; Turner, et al., 2005). Parents felt their health care practitioners avoided discussions about this topic (Turner, et al., 2007). They were left to deal with this issue alone thus many failed to initiate a discussion about their

cancer with their children (Turner, et al., 2007). Some parents were reluctant to discuss the illness with their children, believing that telling too many details about their cancer would negatively affect their children (Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009).

When women did find parenting resources for cancer, they reported the materials were mostly aimed at early stage cancer. Several women recounted that professional help and assistance offered by counselors or cancer service agencies were irrelevant and inappropriate for mothers with advanced cancer, especially regarding how best to approach the topic of death with children (Turner, et al., 2007). Women reported depending on personal experiences or experiences of people they knew on how best to communicate their cancer and its implication to their children (Bell & Ristovski-Slijepcevic, 2011; Turner, et al., 2007). When recounting these experiences, women commented on the negative emotions they or their friends felt when their own parent's cancer was not disclosed to them or was purposely obscured. They were "bitter" and "angry" or distressed. These findings suggest parents need help communicating with their children about advanced cancer in order to maintain the parent child relationship and trust.

Worrying about emotional impact on children. Parents often reported concerns about the emotional impact the parent's cancer had on their children (Bell & Ristovski-Slijepcevic, 2011; O'Callaghan, et al., 2009; Turner, et al., 2007; Turner, et al., 2005). Some parents worried less about the impact of the disease on themselves than about its effect on their family and children (Houldin & Lewis, 2006). One study revealed a

consensus upon a 'hierarchy of suffering.' This hierarchy was an often times unspoken agreement that living with advanced cancer was far worse when the women had dependent children (Bell & Ristovski-Slijepcevic, 2011). This finding was supported in another study where women reported seeing the emotional impact of their cancer on their children was the most difficult piece of their cancer experience (Turner, et al., 2005). Parent's also reported concerns about their family, especially their children, watching their physical deterioration (Bell & Ristovski-Slijepcevic, 2011; Turner, et al., 2005).

Most parents described their children as being upset by the news of their cancer diagnosis. They described their children's distress such as crying uncontrollably or asking "how many sleeps" until the parent died. Some parents acknowledged the impact of their diagnosis on their children, while others believed their children had not been impacted by their diagnosis (Kennedy & Lloyd-Williams, 2009).

Impact on Children & Adolescents

Psychosocial impact. While quantitative studies of the impact of parental advanced cancer on adolescents are rare, there are several studies that included parents with advanced cancer in their samples. Although the results of these studies are aggregated across all stages of cancer, they have identified factors related to children's adjustment that may be important to consider when examining families dealing with advanced cancer. For instance, recurrence of parental cancer has been associated with high rates of distress and stress response symptoms in adolescents (Huizinga et al., 2005; Huizinga, Visser, Van der Graaf, et al., 2011). Studies have also found that the severity of parent's physical impairment and a perception of the illness as more serious are factors

strongly related to greater distress in adolescents (Brown et al., 2007; Compas et al., 1994; Compas, Worsham, Ey, & Howell, 1996; Lindqvist, et al., 2007). It can be inferred from these studies that examined parents with all stages of cancer that experiencing a parent with advanced cancers may have similar psychosocial outcomes for children.

Siegel and colleagues (1992) found that children whose parents were receiving treatment for advanced cancer reported significantly higher levels of depression, anxiety, and lower self esteem than peers. In addition, parents reported higher behavioral problems and lower social competence in the children with a terminal parent (Siegel, et al., 1992). In a follow up study Siegel et al. (1996b) found these children's levels of depression and anxiety prior to their parent's death were significantly higher than it was 7-12 months after the loss of their parent; suggesting the terminal phase of a parent's illness may in fact be a period of more distress than after the actual loss. A recent study by Rainville et al. (2012) found that adolescents living with a parent's advanced cancer showed significantly higher levels of distress and depression compared to the general population. Upon further analysis they discovered age effects on their results with early adolescence defined as 12 to 14 years showing no significant differences in measures when compared to the same age group of peers. However, late adolescents (15 to 18 years) continued to show significant differences in their levels of distress, anxiety, and irritability compared to their peers (Rainville, et al., 2012).

It has been shown that depressive mood or negative affect in the parent with cancer is associated with emotional and behavioral problems in children (Sigal, et al., 2003). Further findings show negative parenting behaviors (as assessed by a parenting

behaviors questionnaire) are associated with negative child outcomes such as increased externalizing symptoms (Sigal, et al., 2003). Behavioral problems were also reported in children by parents who did not have open communication styles; however, these parents pointed to the adolescent's age and not the cancer as the reason for the behavioral problem (Kennedy & Lloyd-Williams, 2009).

The qualitative studies reviewed provide further insight and context to these results. Adolescents' reported the knowledge that their parent's cancer had spread or was incurable as very distressing, upsetting and heartbreaking (Beale, Estela A., Sivesind, D. , & Bruera, E. , 2004; Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). They reported feelings of intense sadness and guilt accompanied by concerns about impending parental death and concerns for their own health (Beale, Estela A., et al., 2004; Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). These studies bring to light the adolescent's ability to empathize with their ill parent and show a deep level of understanding and awareness of the ramifications of advanced cancer.

Parent child relationships. There is evidence of a relationship between parenting quality and child and adolescent adjustment to a parent's illness (Sigal, et al., 2003). The significance of the adolescent's relationship with their parent was reported by many of the adolescents interviewed; a positive relationship before the diagnosis seemed to help adolescents adapt to the changes brought about by the illness (Christ, et al., 1994). Open communication between the parent and child led to more effective coping and also seemed to strengthen the parent child relationship (Kennedy & Lloyd-Williams, 2009). Children and adolescents often described a consequence of the illness of spending more

time with their parent and as a result "a sense of becoming closer to their family" (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011). Sheehan & Draucker (2011) found that adolescents spent more time together with family and extended their time together by developing strategies to maintain their relationship after the parent's death. These findings imply that warm and supportive parenting may serve as a protective factor for these children and adolescents.

Coping strategies. Lazarus (1993, p. 237) defines coping as "ongoing cognitive and behavioral efforts to manage specific external demands that are appraised as taxing or exceeding the resources of the person." Emotion focused coping is the "regulation of stressful emotions" and problem focused coping is "the management or alteration of the person-environment relationship that is the source of the stress" (Folkman & Lazarus, 1988; Lazarus, 1993). In other words, emotion focused coping is when the child attempts to modify their own reactions to their parent's cancer and problem focused coping is when the child makes attempts to modify the cancer or stressors related to the experience (Thastum, Johansen, Gubba, Olesen, & Romer, 2008). The literature shows children and adolescents who have a parent with advanced cancer utilize one or more of these coping styles.

Two studies specifically looked at children and adolescents coping styles when faced with a parent's advanced cancer (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). They found both emotion focused and problem focused strategies were employed by adolescents faced with a parent's advanced cancer. Kennedy et al. (2009) found the two most common coping strategies used were an emotion focused coping strategy,

distraction to maintain normalcy in their daily lives and the problem focused strategy of talking to someone outside of the family about the cancer. Christ et al. (1994) described common ways of coping for adolescents who had a parent with advanced disease including "intellectual defenses, search for understanding, and ability to seek help."(p.8) Adolescents were found to be aggressive in seeking information about the disease from various sources (parent, medical staff, books, etc.). Many adolescents desired more communication about the illness, either factual or emotional (Beale, Estela A., et al., 2004; Bugge, Helseth, & Darbyshire, 2008b; Kennedy & Lloyd-Williams, 2009). At times they expressed a desire to talk to somebody outside of the family about their concerns in order to lessen the burden on their parents (Bugge, et al., 2008b; Kennedy & Lloyd-Williams, 2009). Adolescents tried to obtain meaning from the cancer experience, and the role it played in their lives and their family (Christ, et al., 1994; Sheehan & Draucker, 2011). Finally, adolescents seemed to cope by eliciting social support from peers, parents, and other adults and professionals (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009).

Caregiving. Although parent's described their efforts to maintain normal daily routines for their children, many adolescents reported increased demands to help with household chores (Beale, Estela A., et al., 2004; Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). A majority of children described becoming a caretaker for their ill parent (Beale, Estela A., et al., 2004). Adolescents would run errands and try to take care of family needs in hopes of "making it better for the ill parent" (Sheehan & Draucker, 2011). For some, the added family demands became stressful as it interfered with their

regular activities (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009) but many adolescents welcomed the ability to help as a way to feel better about the situation (Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011).

Positive gains. The prevalence of positive well being is rarely addressed in the literature on parental cancer. But in the case of advanced cancer, positive aspects of the cancer experience seem to consistently emerge from the findings. Many of these studies have unexpectedly found evidence of resilience or protective factors that have led to a positive outlook for these families. Sheehan & Draucker (2011) found that parents and adolescents spent more time together, increased intimacy and continued to foster a sense of attachment after the parent's death. Kennedy et al. found that parents and children reported a greater sense of appreciation for their family and a sense of "being grateful for what they have"(2009, p. 890). As one adolescent shared, "(Cancer) awakens your love for someone, you know" (Christ, et al., 1994, p. 611). Many adolescents seemed to search for meaning in the cancer experience as a way to cope and maintain hope (Christ, et al., 1994; Sheehan & Draucker, 2011). Parents also reported witnessing positive outcomes in their children such as increased independence, learning to prioritize, and improvements in relationships with family members (Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011).

Intervention Studies

Theoretical frameworks. Three studies explicitly identified a theoretical framework as the basis of intervention and one study reported no framework. Adams-Greenly (1983) used Piaget's Theory of Cognitive Development as a way to understand

children's perceptions of illness and death and as a basis for their psychosocial interventions. Bugge and colleagues (2008b; 2009) reported using coping theory and the family resiliency theory to create their family based approach to enhance positive parent child relations. Although Kennedy et al. (2008) did not report a theoretical framework used in the design of the intervention they did describe using Family Systems Theory to guide their analysis of the results of the evaluation.

Intervention components. All studies focused on individual and family therapy sessions and individualized care based on the counselor's assessment of the family's needs. The professionals providing services varied and included nurses, sociologists, social workers, and art therapists. All three studies focused on the final phases (parent < 6 months survival) of the parent's illness trajectory for the intervention. Duration of the intervention varied across the studies, from a limited 4-6 week intervention to ongoing support provided during parent's illness and after their death that was based on family needs.

Many of the interventions were based on clinical observations of need for such programs, age-related concerns of children, and relevant research findings. Most of the programs had similar goals and components, including (1) education: educating children about cancer and medical treatment; providing parent's psychosocial, developmental, and parenting advice; (2) normalization: creating a safe environment which allows families to express their feelings and thoughts as well as provides them with psychological/emotional support; (3) building on existing strengths: helping families

recognize their ability to cope with stressful events and further enhancing their coping skills; (4) helping children and families prepare for death and face the future.

Bugge et al. ((2008b; 2009) created the Family Support Program for children aged 5-18 years old who had a parent diagnosed with incurable cancer. Their goal was to enhance protective factors for families by focusing on positive interactions between family members about the illness. The intervention consisted of 5 sessions, the first being a family meeting introducing the program to parents and children. The second meeting was conducted just with the parents and focused on parenting and family coping with the illness. The third meeting consisted of individual meetings with each child where they would create social network maps of people who the children identified as supportive through the illness experience. The interventionists also focused on answering children's questions about the cancer and providing information about possible coping strategies. The final two sessions were family meetings focused on identifying family strengths that could help them cope with the illness, prepare for the future, and identify additional support if needed.

Kennedy and colleagues (2008) conducted a program evaluation of Macmillan Cancer Support agency but provided limited details about the specific interventions used by the social workers. They emphasized that the social workers were trained in end of life care and used "skilled interventions" individualized to the family's needs. Support was provided before, during and after the parent's death for as long as the family required support.

Adams-Greenly & Moynihan (1983) describe psychosocial interventions developed by a hospital social worker to meet the needs of terminal patients and their children. They provide a general overview of various suggested interventions including: enlisting the parents' aid to support their child, providing age appropriate information to the children about the cancer, arranging hospital visits to see their ill parent with appropriate preparation and support, interpretation of medical status for the child, and preparation for the death of their parent. They stress that follow up contact with families after the funeral is important to prepare families for the process of bereavement. They suggest providing the surviving parent with information about normal developmental reactions to grief to facilitate their support of the children.

Designs. The studies included in this review all used qualitative program evaluation designs, with one study using a pre and post intervention evaluation design (Kennedy, et al., 2008). Bugge (2008a; 2009) conducted in –depth interviews with children and parents then analyzed their feedback using a phenomenological perspective. Finally, Adams-Greenly (1983) used no formal evaluation methods and reported findings based on informal verbal feedback from participants and the author's own impressions.

Findings. All of the studies reported positive outcomes using varied evaluative methods (Table 2.3). Most of the intervention programs obtained an informal evaluation from children, parents/caregivers, and/or staff through methods such as verbal comments from participants, and interviews. Feedback from these sources revealed that the effects of these intervention programs on children and their families were clinically positive.

Bugge et al. (2008b; 2009) used in-depth interviews to evaluate the Family Support Program designed for parents who have terminal cancer. Their findings suggest the program's combination of family, child, and parent meetings with a therapist ultimately helped the children become: more secure, aware of the support systems available to them, and more informed and able to communicate about their parent's illness (Bugge, et al., 2008b). Parents reported the program helped them to gain insight into their children's thoughts and reactions to the illness. Parents also reported a reduction of conflicts, better communication, and greater confidence in their ability to help their child cope (Bugge, et al., 2009).

Kennedy et al. (2008) concluded the holistic family focused approach of providing services before, during and after a parent's death was 'highly valued' by the families and stakeholders. It was noted that the intense and all encompassing nature of the bereavement specialist's role and complexity of the interventions provided would be difficult to sustain or transfer to other settings.

Discussion

Methodological & Conceptual Issues

Quantitative study designs. The majority of these studies were cross sectional, with only one study using a longitudinal design (Siegel, et al., 1996b). Rubin & Babbie (2008) explain how cross sectional designs have an inherent problem. In general, they seek to understand causal relationships that are part of processes that take place over time, however, their findings are determined by an observation made at a single time

point (Rubin & Babbie, 2008). While cross sectional designs do not allow us to make causal inferences, they do provide valuable insights as to which variables are related to each other and should be examined more closely in further research. Longitudinal research seems particularly important in this research area in order to assess which stage of the illness may be most critical for intervention and to examine the long term consequences of advanced cancer on these emerging adults.

Samples. There are a myriad of sampling issues to consider when reviewing the empirical data on advanced parental cancer. The majority of studies in our review had an extremely small sample sizes with only 1 study nearing 100 participants (Siegel, et al., 1996b). This makes it difficult for most statistical analysis to reach statistical power. Small sample sizes also compound the difficulty in evaluating differences in child adjustment based on gender, age, and levels of cognitive maturity.

The preponderance of participants in all the studies reviewed were also Caucasian, educated, and in middle or high socioeconomic class. Thus, these homogenous samples diminish the external validity of these studies (Rubin & Babbie, 2008). Another problem with the sampling methods of these studies is they require voluntary participation from the parents and children. Many of them rely on self referred families in which the adolescent has been informed of their parent's advanced cancer diagnosis. One study attempted to understand these self selection effects by using multi level analysis to compare the stress response symptoms (SRS) of adolescents and ill parents who were self referred to those recruited by hospital staff (Huizinga, Visser, Van der Graaf, et al., 2011). They found adolescents who self referred to the study had more

emotional problems and higher SRS than those recruited by hospital staff. In addition, self referred ill parents had higher levels of anxiety. These findings highlight the importance of paying attention to the effects of selection bias when recruiting from different sources and when comparing studies that used different recruitment techniques (Rubin & Babbie, 2008). Furthermore ethical and methodological issues prevent researchers from being able to assess the impact of a parent's advanced cancer on adolescents that have not been told about the diagnosis. Thus, retrospective studies are needed to address such questions.

In addition many of these studies aggregated various developmental age groups together and defined them as "children". Researchers need to distinguish a more restricted conceptualization of "children" because each period of childhood has its own set of biological, developmental, and psychosocial issues. Research studies should be tailored to each developmental level in order to obtain a clear understanding of the needs of adolescents in each developmental phase. In particular there are limited studies of the experience of adolescents in this population although they have been identified as a potentially vulnerable group. Thus more studies should focus on the adolescents' experience by examining differences between early and late adolescents' outcomes.

Measurement. The primary method of data collection in these studies of the effects of advanced parental cancer on children involved parent and self report. Most used preexisting measures that had adequate reliability and validity. But, self report questionnaires can be subject to self reporting bias and may be unreliable. The best

measurement instruments can be hindered by biases such as social desirability, distortions of reality, poor recall, and denial (Rubin & Babbie, 2008). Few of the studies acknowledged that solely using self report and parent reports subjected them to self reporting bias and none attempted to triangulate their data with more objective measures or examine cross informant correlations.

Another important limitation to the studies reviewed was the choice of measures and constructs examined showed a trend toward using symptom checklists aimed at identifying psychopathology. None of the studies made an attempt to measure the children's quality of life. This is surprising due to the abundance of quality of life measurements used when studying children with cancer or adult psychosocial oncology. The use of quality of life measures seems to be appropriate for this population due to the normative distress of having a parent with cancer which puts children and adolescents at increased risk of maladjustment but also allows for the possibility of resilient individuals in the samples (Krattenmacher, et al., 2012).

Qualitative Studies. The concept of quality or rigor in qualitative studies has been an issue of controversy for some time (Creswell, 2007). Armour et al. (2009) described rigor as "the degree to which researchers hold themselves to standards of inquiry that address challenges to the credibility of the studies findings." (p.102) Therefore in our review we will evaluate methodological thoroughness as well as strategies used to ensure trustworthiness.

The participants interviewed were overwhelmingly parents (eight studies) and only one study focused solely on the adolescents' experience. The credibility of some of the qualitative studies was also limited by inadequate descriptions of their methods of analysis (Beale, Estela A., et al., 2004; Christ, et al., 1994; Turner, et al., 2007; Turner, et al., 2005).

Qualitative validity. Lincoln and Guba (1985) suggested the concept of trustworthiness as a way to ensure quality in naturalistic research designs. Since then, qualitative researchers have put forth various criteria that can be used to assess a study's authenticity or trustworthiness and strategies that can be used to achieve rigor (Creswell, 2007; Johnson, 1997). Creswell (2007) recommended researchers employ at least 2 of these strategies in any given study to achieve adequate trustworthiness of their findings. Seven of the included studies used two or more of these strategies to ensure trustworthiness including use of field notes, clear description of analysis, direct quotations from participants, rich thick descriptions, extended field work, peer review, reflexivity, investigator triangulation, data triangulation, inter-coder reliability, and audit trails (Bell & Ristovski-Slijepcevic, 2011; Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; O'Callaghan, et al., 2009; Sheehan & Draucker, 2011; Turner, et al., 2007; Turner, et al., 2005)

Intervention studies. The relative absence of intervention studies makes it difficult to draw conclusions about interventions for children and adolescents' facing a parent's advanced cancer. We do not know how or what to do to best help the children

and it is much easier to describe than to intervene (Rauch, 2007). The results of the four intervention studies reviewed may be clinically significant and show promise that providing support for parenthood and children during the terminal phase of illness may provide psychological well being for families facing parental death from cancer. More importantly these studies show interventions do not cause harm. Nevertheless the gains provided by these studies are not convincing from the perspective of intervention research due to study designs and various limitations. One of the primary limitations was the lack of a control group in the studies, greatly decreasing the reliability of the intervention effect. Lack of formal instruments was a significant threat to validity for all studies. Internal validity was compromised in all the studies in varying degrees. Selection was a significant threat in that all the samples were comprised of volunteer participants, potentially biasing towards more positive outcomes. Also, future studies are needed using experimental designs that control the independent variable to validate the causal inferences of newly developed interventions and to ensure outcomes are trustworthy. Despite the methodological limitations, the reviewed studies lend support to the benefits of psychosocial programs in helping children adapt to advanced parental cancer: promoting positive parenting, decreasing misconceptions about the illness, providing opportunities for expressing feelings, increasing family communication and promoting positive coping. Researchers need to continue in their interventional efforts and evaluative research in order to satisfy the current lack of evidence to guide clinical practice

Conclusion

The results of this analysis of literature have shown the paucity of research on the adolescent's experience when a parent has advanced cancer. From this review of literature we know adolescents' living with a parent's advanced cancer show significantly higher levels of distress, anxiety and depression as well as lower self esteem than their peers (Rainville, et al., 2012; Siegel, et al., 1996b; Siegel, et al., 1992). In addition, parents reported higher behavioral problems and lower social competence in the children with a terminal parent (Kennedy & Lloyd-Williams, 2009; Siegel, et al., 1992). These findings suggest the end stages of a parent's illness may be a particularly vulnerable period for adolescents.

Possible factors that impact the adjustment of adolescents to their parent's advanced illness include poor parenting, open communication style, age (early vs. late adolescence), and the parent child relationship (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009; Rainville, et al., 2012; Sigal, et al., 2003). Adolescents used a variety of coping strategies when faced with a parent's advanced cancer (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). The most common included: distraction to maintain normalcy, talking about the cancer and not talking about it, reasoning, helping the ill parent, searching for meaning, and seeking social support. Most studies discovered families facing advanced cancer employ positive outlook and hope as strategies to overcome the challenges and uncertainties of their experience. As a result possible resilience or protective factors were identified.

From the reviewed studies we know that parents are concerned about the best ways in which to talk about their advanced cancer with their children; try hard to maintain normalcy in their children's lives; strive to be good parents; and are concerned about the emotional impact their cancer has on their children. However, there is still much we do not know about the experiences of adolescents living with a parent with advanced cancer. We lack studies that examine the specific concerns parents have about their adolescent children's behavior; an understanding of the adolescent's experience from their own perspective; the difficult situations faced by the adolescents in relationship to the parent's advanced cancer; the parent-adolescent relational issues; and what parent's tell their adolescents about advanced disease diagnosis. Therefore more descriptive research focused specifically on adolescents is needed to inform development of effective interventions for this at risk population.

Future Research

There are still large gaps in the literature on children and adolescent's adjustment to advanced parental cancer. This review of literature and methodological critique aimed to highlight challenges in this area in hopes to inform future research. The following recommendations are offered:

1. Longitudinal studies are needed to assess the causal and long term effects of advanced parental cancer. In addition, longitudinal designs will allow for a better understanding of how children's adjustment may change over time (diagnosis, treatment, end of life, and post-death).

2. Assessment of children and adolescent's quality of life and not just clinical levels of psychopathology are needed.
3. Examination of the experience of adolescent's when a parent has advanced cancer, from their own perspective.
4. Triangulating data collection in the form of methodology (quantitative and qualitative) and informants (child, parent, teacher, HCP) to increase reliability.
5. Studies with larger and more diverse samples are needed to reflect the population of families facing advanced cancer in the United States.
6. Focus on identifying risk and protective factors that affect children's and adolescent outcomes when dealing with a parent's advanced cancer diagnosis.
7. Intervention studies using control groups and validated measures to assess the efficacy of the programs.

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Table 2.1 Parent Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Bell & Ristovski-Slijepcevic, (2011) Canada Metastatic cancer and mothering: Being a mother in the face of a contracted future	Mixed Metastatic Cancer (breast, blood, colorectal, ovarian, uterine, stomach, and lung cancers) Support group N= 6-12 ill women Interviews N= 4 of the group members with children ages 4-18	Qualitative – Longitudinal Ethnographic exploration of the impact of metastatic cancer on women who are mothers of dependent children.	Support groups, interviews of women with metastatic cancer. Ethnographic Field work	This article reflects on the experience of mothers facing metastatic disease which seems entrenched in cultural discourse on mothering. These women are forced to choose between focusing solely on their children's needs and focusing on themselves and both seemed unrealistic. **Hierarchy of suffering-** living with metastatic cancer was far worse when the women had dependent children **Need to maintain sense of normalcy-** Pressure identified by the mothers to maintain normalcy for their children above and beyond their own needs with failure resulting in maladjusted children **"Cram Parenting" and "Making memories"-** Race against time, parenting may feel artificial, inauthentic as you try to cram 20 years worth of parenting into a few short years, trying to create as many memories as possible in a short amount of time

Table 2.1 Parent Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
O' Callaghan et al., (2009) Australia Resounding attachment: Cancer inpatients' song lyrics for their children in music therapy	Metastatic or Hematological Cancer – Inpatient N= 12 (3 fathers, 9 mothers) 23 children ages 1- over 18	Qualitative . To explore how song writing may support parents and children through the cancer experience, according to attachment, developmental, and bereavement theories.	Date = Song lyrics written by ill parents Grounded Theory – comparative analysis	Parents' song lyrics messages may support their children during the parent's illness and through the children's developmental transitions and bereavement. A catharsis for parents and to encourage attachment to parent after death. Song Lyric Categories **1. Affirmation, support, and encouragement** **2. Play songs** **3. Parents describe and compliment children** **4. Express longstanding, enduring love** **5. Description of parent's effort, worry, loss, sadness, grief** **6. Compliments and descriptions of others** **7. Children can help their parents** **8. Hopes and wishes for children** **9. Messages & requests for comfort, support, existential beliefs** 10. **Positive reminiscences and predictions**

Table 2.1 Parent Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Turner et al., (2007) Australia Development of a resource for parents with advanced cancer: What do parents want?	Advanced Breast Cancer N= 8 mothers Diagnosis of advanced cancer, 8 weeks-10 years Age of children at diagnosis: 2-13 y	Qualitative Determine the specific needs of parents with advanced cancer in relation to their children, access to resources, and relevance of existing research	Structured telephone interviews	**Themes:** **Assistance Offered by Health Care Professionals** HCP's avoid discussion about impact on children Offered a list of books **Usefulness of Existing Resources** Few addressed metastatic disease No way to assess quality **Experiences of Seeking Assistance** Counselors not aware of needs/helpful Peer support groups helpful **Experiences of Talking with Children about Cancer** Children told about diagnosis of early cancer Need to maintain hope while being honest **Responding to Questions about Death** Need to maintain optimism Feeling they can't be 100% honest **Drawing on Experience: Women's Experiences of Not Being Told** Personal experiences and those of others shaped communication decisions **Things That Have Helped** Honesty, staging information, routine, involvement of children in treatment, getting support for self, accepting help, telling the school

Table 2.1 Parent Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Houldin & Lewis, (2006) USA Salvaging their normal lives: A qualitative study of patients with recently diagnosed advanced colorectal cancer	Advanced Colorectal Cancer (Stage III-IV) N=14 patients (9 men, and 5 women, 10 had children ages 2-25)	Qualitative – Cross Sectional Describe the experiences of patients living with newly diagnosed stage III or IV colorectal cancer	Semi-structured interviews Inductive content analysis	Themes related to parenting - **Rethinking Parenting** Struggle with how to tell the children Spending more time with their children Wanting to reassure their children of positive outcomes Do things differently, listen more **Worrying about family/kids**

Table 2.1 Parent Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Turner et al., (2005) Australia Psychosocial impact of newly diagnosed advanced breast cancer	Advanced Breast Cancer N=66 ill women 56% younger than 55 y 89% mothers 79% with metastatic disease Diagnosis of recurrent or metastatic disease, mean 9.7 weeks (SD 8.9) Age of children: unspecified	Mixed Methods – Cross Sectional Investigate key emotional concerns of women newly diagnosed with recurrent or metastatic breast cancer	Semi-structured Interviews Content Analysis HADS IES CARES-SF MSAS	Quantitative analyses based on number of children, sex of children, and mean age of children found none to be predictive of current distress of quality of life. Qualitative themes related to parenting **The Emotional Impact** 35.8% of women described the emotional impact on their family as the hardest thing about advanced cancer including their children's grief, and guilt and jealousy of missing out on future family time. **Concerns about the family** 55.2% of the women described concerns about the impact of the cancer on their children, including uncertainty about how to discuss the disease and concerns about children watching them deteriorate. 56.7% of women younger than 55 y qualify as 'cases' on HADS compared to 34.5% of women aged over 55 y Women younger than 55 y had significantly higher levels of intrusive and avoid symptoms than women over 55 years Key themes: 1) Difficulties in communicating with doctors, 2) Perceived delay in diagnosis, 3) The

Table 2.1 Parent Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Sigal et al., (2003) Canada Maternal preoccupation and parenting as predictors of emotional and behavioral problems in children of women with breast cancer	Breast Cancer 45 non-metastatic 42 metastatic N= 27 children (16 sons, 11 daughters 6-11 years) N= 60 adolescents (30 sons, 30 daughters; 12-18 years) Comparison of metastatic vs. non-metastatic	Cross Sectional To test the differences between mothers with metastasized breast cancer and mothers with non-metastatic cancer in their preoccupation with their illness and parenting behavior and the subsequent effects on the children's adjustment.	CBCL YSR SWS -self esteem PRQ - parenting IES CIQ –maternal preoccupation	No data reported on children's level of adjustment. - Mothers with metastasized breast cancer reported fewer externalizing problems in their children and less poor parenting. - Children rated mothers with metastatic disease lower on poor parenting scale than mothers with non-metastatic disease - For mothers with non-metastatic cancer internalizing symptoms in their children were predicted by mood rather than parenting behavior.

CARES-SF=Cancer Rehabilitation Evaluation System Short Form, CBCL = Child Behavior Checklist, CIQ= Cognitive Intrusive Questionnaire, HADS= Hospital Depression and Anxiety Scale, IES= Impact of Event Scale, MSAS=Memorial Symptom Assessment Scale, PRQ= Parent's Report Questionnaire, SWS= Self Worth Scale, YSR= Youth Self Report

Table 2.2 Child Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Rainville et al., (2012) Canada Psychological distress among adolescents living with a parent with advanced cancer	Mixed Advanced Cancer 32% lung, 16% digestive, 21% gynecological, 32% other N= 19 families N= 28 adolescents (10 sons, 18 daughters 12-18 years) Comparison group-community sample (ESSEA) N=2,346 adolescents	Cross Sectional To determine to what extent adolescents who have a parent with advanced cancer experience more psychological distress than adolescents in the general population.	IDPSQ-14 - (psych. distress) Recent stressing events questionnaire	Sample: Ill Parent M(SD) / Community M(SD) **IDPSQ-14** Distress Index: 25.36(5.91)* / 23.19(7.72) Subscales Depressive: 9.04(2.35)* / 8.11(3.31) Anxious: 5.87(2.03) / 5.41(2.17) Irritability: 7.54(2.15) / 6.98(2.75) Cognitive Problems: 2.93(1.36) / 2.76(1.26) *p<.05 - adolescents with an ill parent had significantly higher levels of distress and depressive state compared to adolescents with a healthy parent -Late adolescents (15-18) had significantly higher distress, anxiety, and irritability compared to norms of the same age -Late adolescents experienced significantly higher distress, and anxiety than early adolescents (12-14) with an ill parent

Table 2.2 Child Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
*Sheehan & Draucker, (2011) USA Interaction patterns between parents with advanced cancer and their adolescent children *includes adolescent and parenting outcomes	Mixed Advanced Cancer Hospice Care N= 9 ill parents N= 7 spouses N= 10 adolescent (ages 12-18)	Qualitative – Cross Sectional To develop an explanatory model that explains interaction patterns between parents with advanced cancer and their adolescent children.	Semi structured interviews with adolescents & parents Constructionist Grounded Theory	Time was of great importance to these parents and adolescents; all participants structured their stories in relation to the concept of time. A model was created that reflected the dynamic process by which families adapted their relationships in the face of advanced cancer. **Not having enough time together** Time with their children was limited due to terminal illness and expressed regrets about not spending more quality time before the illness, loss of future time **Making the most of the time we have left by:** Coming to know the time we have is limited Spending more time together becoming closer Extending our time together – finding ways to transcend boundaries of time and death Giving up our time together to end suffering
*Kennedy & Lloyd-Williams, (2009) England How children cope when a parent has advanced cancer *includes adolescent and parenting outcomes	Mixed Advanced Cancer N= 12 families N= 10 ill parents N=7 well spouses N= 11 children ages 8-18 years	Qualitative – Cross Sectional Explore the impact of parental advanced cancer on children and how they cope, from the perspectives of children and parents.	Semi-structured interviews with parents and children Constructionist Grounded Theory	Open communication within the family may lead to more effective coping and a positive experience for children whose parents have advanced cancer. Major Themes: **Response to diagnosis** Children described being distressed and having concerns related to their parent's health and their own. **Mechanisms of coping** Distraction and maintaining normality described as major coping strategies **Life changes** Increased responsibilities and decreased social activity most noticeable life changes **Positive aspects** Strengthening relationships and learning to value family members and the important things in life seen as positive aspects

Table 2.2 Child Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Beale et al., (2004) USA Parents dying of cancer and their children	Mixed Advanced Cancer Palliative Care N= 23 children (ages 3-18) with an ill parent N= 5 children with an ill sibling	Descriptive (Qualitative) To report the experiences of children of parents with terminal cancer.	One or more clinical interviews with children.	**Child Reported Emotional Domains** **% of children** Seeks reassurance 82% Becomes caretaker 79% Separation ability 79% Anger about abandonment 68% Despair 57% Guilt 54% Discipline problems 46% Aggressive behavior 43% Reliance or denial 39% Blame others 21% Fear for own health 18%

Table 2.2 Child Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Siegel et al., (1996) USA Adjustment of children facing the death of a parent due to cancer	Mixed Advanced Cancer Patient died within 1 year of first measures, post-death measures taken within 7-12 months of the loss N=70 families N=97 (60 children ages 7-11, 41 ages 12-17) *ages pre-death Comparison Group-Community Sample N= 467 families N=616 children	Longitudinal study sample Cross Sectional Comparison group To compare pre-death and post-death levels of depression and anxiety reported by a sample of children who lost a parent to cancer along with levels reported by community sample.	CDI STAI-Y STAI-C	Community Sample M(SD) / Study M(SD) **CDI** Pre-death*** 46.0(10.4) / 50.7(11.0) Post-death 46.1(10.5) / 45.5(9.6) **STAI** **State** Pre-death*** 45.6(10.2) / 52.3(11.5) Post-death 45.1(10.2) / 45.9 (10.3) **Trait** Pre-death*** 44.6(12.3) / 50.8(11.5) Post-death 45.2(11.8) / 45.7 (11.6) ***p< .001 - Children facing the death of a parent reported significantly higher levels of depression and anxiety compared to community children - 7-12 months after the loss of their parent the same children reported on average the same levels of depression and anxiety as those reported by the community sample

Table 2.2 Child Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Christ et al., (1994) USA Impact of parental terminal cancer on adolescents	Mixed Advanced Cancer N= 86 families N=120 adolescents (ages 11-17 years)	Qualitative – Cross Sectional Summary of psychological and emotional responses to a parents advanced illness as described by adolescents	Assessment interview of adolescents	Compared to younger children the adolescents greater cognitive and empathic capacities allowed them to be more aware of losses and of the parent's physical and emotional pain. Parental cancer precipitated conflict around issues of developmentally appropriate separation. The capacities to use intellectual defenses, search for meaning, and seek help were powerful coping strategies. **Interview Responses:** Emotional Control Intensification of Typical Adolescent Themes **Problems & Concerns:** Empathy for ill parent Increased involvement with parents Household responsibilities Influence of parental relationship Guilt **Common Ways of Coping** Intellectual Defenses, The search for understanding, Seeking help **Severe Reactions**

Table 2.2 Child Outcomes				
Source(Year)/ Country	**Subject Description/ Sample (N)**	**Study Design/Purpose**	**Measures/ Methodology**	**Results/Findings**
Siegel et al., (1992) USA Psychosocial adjustment of children with a terminally ill parent	Mixed Advanced Cancer Parent died within 6 months of interview N=62 children ages 7-16 (55 children ages 7-11, 45 children ages 12-16) N=42 ill parents Comparison group-community sample N=556 children N=434 families	Cross Sectional To describe children's reactions to a parent's terminal illness using child and parent reports.	CDI STAI-Y STAI-C SEI CBCL	Community Sample M(SD) / Study M(SD) **CDI*** 6.8(7.0) / 10(6.5) **STAI-C** State* 27.7(5.9) / 32.8(6.5) Trait* 31.0(6.6) / 37.4(4.9) **STAI-Y** State* 36.8(10.7) / 46.8(12.5) Trait 40.4(11.2) / 44.6(9.1) **SEI*** 76.8(19.7) / 68.8(19.4) **CBCL** Internalizing* 47.1(8.6) / 55(10.5) Externalizing* 46.1(8.2) / 52.2(10.8) Total Problems* 45.7(9.6) / 54.6(11.5) *p<.05

CBCL= Child Behavior Checklist, **CDI= Child Depression Inventory, IDPSQ-14= Indice de Detresse psychologique de Sante Quebec (derived from Psychiatric Symptom Index (PSI)), SEI= Self Esteem Inventory, STAI= State Trait Anxiety Inventory, STAI-C =State Trait Anxiety Inventory – children's version**

Table 2.3 Intervention Studies				
Source (Year)/ Study	**Subject Description/ Sample**	**1. Theoretical Framework** **2. Methodology/Evaluation Method** **3. Comparison Group**	**Intervention Components**	**Results/ Findings**
Bugge et al., (2009) Family support program Norway Parents' experiences of a family support program when a parent has incurable cancer	Metastatic Mixed Cancer N= 6 ill parents N=7 spouses Had 12 children ages 6-16	1. Based on coping theory of Libo & Griffith. Family based approach to reduce risk factors and enhance positive interactions between parent and child. 2. Qualitative design: In-depth interviews with ill parents and their spouses up to 6 weeks after completion of the program. Phenomenological-hermeneutical perspective. 3. No comparison group.	- Individual & Family/child & parent intervention - 5 meetings over 4-6 weeks Meeting were as follows: - Family mtg introduce program - Parent's meeting to discuss parenting and coping - Children's mtg talk about each child's experiences, draw social map, draw feelings, discuss medical treatment & questions; --Family mtg to discuss concerns, family strengths assessed; ----------Family mtg how to face the future	**Parent's experiences of impact on family resilience:** **Support received** Help w/talking and telling the children Confirmation of what parents had done well Help dealing w/ difficult questions & tasks Help dealing with feelings & reactions **Reframing the crisis** identifying resources in & out of family using family strengths to make memories/strengthen relationships **Seeking and using help** Planning the future and help needed
Bugge et al., (2008) Family support program Norway Children's experiences of	6 families with a parent with terminal cancer with 12 children ages 6-16	1. Based on coping theory of Libo & Griffith. Family based approach to reduce risk factors and enhance positive interactions between parent and child. 2. Qualitative design: In-depth	- Individual & Family/child & parent intervention - 5 meetings conducted over 4-6 weeks Meeting were as follows:	**Children's main concerns in relation to the illness situation:** Fear that parent would die; Being unable to talk with parents about illness situation; Being sad and frightened, seeing the changes in the parent's condition; Having fantasies and fears about cancer as an illness

Table 2.3 Intervention Studies				
Source (Year)/ Study	**Subject Description/ Sample**	**1. Theoretical Framework 2. Methodology/Evaluation Method 3. Comparison Group**	**Intervention Components**	**Results/ Findings**
participation in a family support program when their parent has incurable cancer		interviews with children up to 6 weeks after completion of the program. Phenomenological-hermeneutical perspective. 3. No comparison group.	Family meeting to introduce program Parent's meeting to discuss parenting and coping during illness Children's meeting talk about experiences, draw social map, draw feelings, discuss medical treatment & questions; Family meeting to discuss concerns, family strengths assessed; Family meeting to focus on how to face the future	**How children experienced the Family Support Program in Relation to coping factor "Belonging":** Confidence to talk about the illness situation; Predictability about illness situation; Talking about family strengths, confirmation, and association within the family; Information sharing with social network about illness situation **How children experienced the Family Support Program in Relation to coping factor "Competence":** Increased knowledge about illness and prognosis; Being important and valuable in the family; Confronting and coping with their own fear and other reactions to the illness situation
Kennedy et al., (2008) Macmillan Cancer Support Scotland Supporting children and families facing the death of a parent	6 families with a parent with terminal cancer with children up to age 19	1. None noted for intervention. Family Systems Theory used for data analysis. 2. Qualitative Pre and Post-intervention evaluation design. Case Study methods using data from in-depth interviews with children, parents, stakeholders, & staff. Additional data included observations, documents, and statistical reviews. 3. No comparison group.	Individual and family sessions provided pre and post death with a social worker trained in end-of –life care.	**Themes:** **Thrown into chaos** Crisis of illness Family in turmoil Routines abandoned **Lost in panic** Kids out of the loop No one to turn to Crying for help **Holding them steady** Family as focus Specialist skills Working together

Table 2.3 Intervention Studies				
Source (Year)/ Study	**Subject Description/ Sample**	**1. Theoretical Framework 2. Methodology/Evaluation Method 3. Comparison Group**	**Intervention Components**	**Results/ Findings**
				Journeying together Preparing to face it Travelling together Remembering together Saying goodbye **The road ahead** Riding the storm Seeking a balance Glimpsing a future Securing the legacy
Adams-Greenly & Moynihan, (1983) Memorial Sloan Kettering Cancer Center USA Helping the children of fatally ill parents	Toddlers through adolescents	1. Piaget's Theory of cognitive development as a basis for psychosocial intervention. 2. No formal evaluations have been conducted. 3. No comparison group.	Parent & child intervention Collaboration with parents and providing them psychosocial knowledge Provide age appropriate info. Arrange hospital visits with adequate preparation and support, Help interpret medical status for child Preparation for death of parent	Author provided descriptions of children's responses and examples of their coping.

Chapter 3

Weaving a Normal Life with Cancer: Adolescents' Experiences When a Parent has Advanced Cancer

Abstract

Parental cancer is a stressful experience for young people, constituting a potential threat to physical and mental health, and normative development. Currently, there is insufficient information describing the nature of this distress when a parent has advanced cancer, especially concerning families with adolescent children. The aim of this study is to address the significant gap in the literature offering the adolescent's perspective regarding the impact of their parent's advanced cancer on their lives. This qualitative study involved single occasion, semi-structured interviews with adolescents whose parents were diagnosed with advanced stage cancer. In addition, standardized questionnaires of adolescent psychological functioning were completed. The study sample consisted of seven adolescents, five female and two male ranging in age from 11-15 years (M=13.6, SD=1.4). The core construct that organized study results was weaving a normal life with cancer. Weaving a normal life with cancer involved five major domains: *feeling the weight of the world on my shoulders, cancer changes everything, strategies-I don't like middle ground, either directly confronting it or going away, talking about it, cancer was a positive for me…it taught me.* Our findings shed light on how families managed when the "terminal phase" of cancer stretched on for many years. Implications for HCP's include the need to facilitate family interventions that provide parents and adolescents with a venue to communicate and process the impact of cancer

on their lives. This may allow for opportunities to reframe the cancer experience and find positive meaning from their challenges.

There are close to 1.58 million cancer survivors in the US with an estimated 2.85 million dependent children living at home (Weaver, et al., 2010). A segment of these parents have advanced, metastatic, or recurrent disease considered incurable. According to the American Cancer Society (2011), cancer is the second leading cause of death in the United States. Approximately, 55,000 US children lose a parent to cancer each year (Weaver, et al., 2010).

Parental cancer is a stressful experience for young people, constituting a potential threat to physical and mental health, and normative development. The struggle with a parent's cancer diagnosis can be very alarming for children and adolescents and often results in psychosocial problems such as "anxiety, confusion, sadness, anger, and feelings of uncertainty with respect to outcome of the illness" (Semple & McCance, 2010). Children's and adolescent's level of distress is even higher during the terminal phase of the disease compared to after the death of the parent (Christ, et al., 1994; Siegel, et al., 1996a). Currently, there is insufficient information describing the nature of this distress when a parent has advanced cancer, especially involving families with adolescent children.

Adolescents with a parent with cancer are at greater risk for depression and anxiety than any other age group (Huizinga, Visser, Zelders-Steyn, et al., 2011). Their increased cognitive abilities and the aptitude for abstract thought make them susceptible

to distress because they are more knowledgeable about the potential future consequences of cancer (Spira & Kenemore, 2000). Adolescents are also more able to accept additional household responsibilities that may diminish involvement in extracurricular activities with peers that support their positive development (Davey, et al., 2005; Pedersen & Revenson, 2005; Sears & Sheppard, 2004; Spira & Kenemore, 2000; Stiffler, et al., 2008). These adolescents often struggle with role changes within the family. They may experience role reversals due to parental cancer in which they become the caregiver for their ill parent. Developmentally, adolescence creates challenges for families as their children strive to gain independence. A developmental task of adolescence is the desire for independence (Erikson, 1994). Adolescents have a strong need for autonomy and may feel guilty when fulfilling these needs. Therefore, they often feel conflicted between meeting the family's needs versus their own (Spira & Kenemore, 2000; Stiffler, et al., 2008).

There are limited data based studies about the experience of families with teenagers of a parent with advanced cancer and most of the available studies focus on the viewpoint and perceptions of the parents. Main findings from these studies show parents have major concerns about how to talk to their children about advanced cancer. In addition, parents also lack appropriate resources and access to professionals to help guide them through parenting issues related to the cancer (Turner, et al., 2007, 2008). Parents also strive to maintain hope and enhance relationships with their children (O'Callaghan, et al., 2009; Saldinger, Cain, Porterfield, & Lohnes, 2004). Ill parents make every attempt to maintain normal routines and a sense of normalcy in the home to protect their

children (Bell & Ristovski-Slijepcevic, 2011; Turner, et al., 2005). Sheehan & Drecker (2011) was the single study that included interview data from the adolescents themselves but focused specifically on interaction patterns between the parent and child. They found both the teen and parent feel the need to make the most of the limited time they have left with each other (Sheehan & Draucker, 2011). Given the paucity of research on adolescents' reports of their experience in living with a parent with advanced cancer the aim of the current study is to address the significant gap in the literature. The purpose of this study was to describe the experience of adolescents living with a parent with advanced cancer.

Methods

After obtaining consent data were collected from seven adolescents, five females and two males. Inductive content analysis was used to code and analyze the interview data subsequently applying the adolescents' own words to develop an explanatory theory of their experiences with advanced parental cancer.

Study Protocol

The study involved single occasion, semi-structured interviews with individual adolescents whose parents were diagnosed with advanced stage cancer. Face to face, in home interviews were completed with the adolescents by trained health care professionals. The interview schedule (Table 3.2) was developed to elicit the issues, concerns, and types and sources of tension or disconnection between the adolescent and the ill parent about the cancer. Audio recorded interviews were transcribed verbatim by a professional transcriptionist and verified against the audio recording prior to analysis.

Standardized measures of adolescent functioning with well-established reliability and validity and prior use in cancer populations were obtained. Adolescent's self-esteem was measured by the Rosenberg Self-Esteem Scale (RSE) a 10-item self-report questionnaire that measures the self-acceptance component (liking or approval of self) of self-esteem (Lewis & Hammond, 1992; Rosenberg, 1965). The Child Behavioral Checklist (CBCL) was used as the parent-reported measure of the adolescent's emotional and behavioral problems. It measures a broad range of 6- to 18-year-old children's behavior problems and social competencies (Achenbach & Edelbrock, 1991). The Youth Self-Report (Achenbach & Edelbrock, 1991; Achenbach, McConaughy, & Howell, 1987) was used as the adolescents' self-report checklist, derived from the Child Behavior Checklist. Finally, adolescent anxiety was measured by the State Trait Anxiety Inventory (STAI) which measures differences in the individual's anxiety state and tendency to react with anxiety (Spielberger & Gorsuch, 1983).

Study Participants

The study sample consisted of seven adolescents from six families. Five female and two male adolescent were interviewed; all were Caucasian. Participants ranged in age from 11-15 years (M=13.6, SD=1.4) and they were in grades from 6th to 10th grade. Parent's types of cancer included breast cancer (2), colorectal cancer (2), and carcinoid (2). The ill parents consisted of four females and two males diagnosed with Stage IV cancer. The majority had lived with cancer more than five years. Mean age was 48.83 years ranging from 43-52 years. Five of the six parents were married with 1.67 children

living at home. The majority (66.7%) had some college or more of education, and earned $70,000 or more.

Data Analysis

Inductive content analysis was used to code the transcribed interview data. The inductive coding methods used were adapted from methods originally described by Glaser and Strauss (1967) and later extended by Lewis and Deal (1995). Analysis began with the bracketing of the author's assumptions about adolescents dealing with a parent's advanced cancer before transcripts were read several times in their entirety in order to understand the meaning of the data as a whole (Moustakas, 1994). The goal of this naïve reading was to grasp a pre-understanding of the author's preconceptions about the subject matter before interpretation began (Grbich, 2007).

Data coding began by unitizing the transcribed data. The unit of analysis was coded as a complete idea, not a complete sentence. Therefore, compound sentences were coded as multiple units (Lewis & Deal, 1995). After unitizing the data, the open coding process began. Open codes were analyzed, compared, and categorized on the basis of the manifest meaning of the text (Houldin & Lewis, 2006; Lewis & Deal, 1995). The categories consisted of coded units that contained common elements. When possible, categories were labeled with emic rather than etic titles using the participants own words (Lewis & Deal, 1995; Strauss & Corbin, 1994). Constant comparative analysis was performed once categories were identified in order to obtain the best fit of each unit within a category, maximum consistency of grouped units, and to validate uniqueness of each category avoiding redundancy (Lewis & Deal, 1995; Strauss & Corbin, 1994).

During the coding process the definitions of categories were formed and continually refined in order to maximize distinction between categories. The author and peer reviewer worked to obtain consensus among the categories and their definitions. Coding consensus was achieved through discussions that resulted in refined category definitions, distinguishing new categories, or moving units of analysis into different categories. Finally, categories were further organized into larger groupings or domains that led to the development of the core category (Lewis & Deal, 1995).

Results

The core construct that organized study results from adolescent interviews was *weaving a normal life with cancer*. The progression of the advanced disease was slow and occurred over many years for these families. Thus many of the adolescents described 'growing up' with their parent's cancer as a part of their lives. The adolescents recognized the fact cancer was beyond their control and they could not make it better. As a consequence, they made every attempt to live a normal life despite the cancer. They created ways to live with it as part of the background rather than a constant focus of their attention. Although the possibility of losing their parent was an impending fear, it was impossible for them to live in a constant state of crisis and apprehension. For that reason the adolescents and their families utilized various coping strategies to allow them to continue moving forward with cancer as only one piece of their life story. Weaving a normal life with cancer involved five major domains: *feeling the weight of the world on my shoulders, cancer changes everything, strategies-I don't like middle ground, either directly confronting it or going away, talking about it, cancer was a positive for me…it*

taught me. These major domains are summarized in Table 3.1 and represent the experiences of having a parent with advanced cancer in these adolescents' lives.

Domain 1: Feeling the weight of the world on my shoulders

Adolescents felt a tremendous sense of responsibility and worry about how their parent's cancer affected their lives in the past, present, and future. Adolescents were concerned about the parent's current state of health and physical limitations and at the same time were apprehensive about the near future and the parent's death. While at home with ill parents they watched the parent's actions closely. They would be concerned if the parent seemed tired, moody, physically ill or emotionally stressed. They seemed hyper aware of the ill parent's emotional and physical state although parents seemed to try and protect them from a 'caregiver role.'

Adolescents were also apprehensive about the distant future, their own health and their future children's reaction. Future concerns included anxiety about the parent's cancer returning or the parent's condition suddenly getting worse. In addition, they were worried about their own future, whether the cancer was genetic and how they would cope if diagnosed with cancer. Thus, these adolescents' entire life trajectory was disrupted by their parent's advanced cancer, not just the present moment. They explained how the most difficult part of the cancer was their lack of control over the disease and how they were unable to make it end. They often felt emotionally isolated from the rest of the family, left to deal with these uncertainties alone. The sense of protecting their family from the tremendous amount of worry and anxiety the adolescents felt was apparent as

they attempted to minimize their intense responses by "taking them back" or explain their parent's lack of attention "didn't bother them."

1.1 Not being able to make the cancer end. When asked what was something hard for them they could not change some responded simply with "That it (cancer) happened to her (mom).", "The fact that the cancer is still there." Some seemed overwhelmed by a sense of helplessness. These adolescents' expressed a frustration with the fact they have no way to make the cancer go away. They responded this was the most difficult part of the cancer experience especially the fact it was something beyond their control. This feeling was summarized by one 15 year old adolescent, "I can't seem to change…well, I can't make it (the cancer) end. It's sort of beyond my control. But I can't make it better, so it's one of those things."

No matter how well they took care of their parent, took on household responsibility, and tried to remain positive, adolescents were not able to change the inevitable: that their parent was going to die from cancer. They felt powerless and felt their parents and doctors were powerless as well. As one adolescent shared, "It is hard that (dad's) going to be gone soon (I can't change that)".

1.2 Feeling alone. Adolescents expressed their desire for more attention and emotional support from their families. They wondered why they were the only ones having to deal with the stress caused by cancer. They described that, especially during treatment, their parents did not have time to pay attention to their children's lives. As one 14 yr old described, "I didn't get as much attention as long as she (mom) had cancer. It

got worse...with chemo and all." When describing things they still needed from their family, emotional needs seemed to surface most often, "Maybe a little bit more positive moral support." Some truly felt like they were left alone with their daunting feelings. As one 13 year old girl described, "Sometimes I'll just feel alone, like I'm the only one dealing with this and it's like having the weight of the world on my shoulders."

1.3 Getting cancer would be a real downfall. All but one adolescent was concerned with the possibility they could be diagnosed with cancer at some point in the future. The disease of 'cancer' was lumped together in their minds and, although they reported causes of cancer to be external such as eating unhealthy foods, stress, and smoking, many reported that cancer could be genetic and they did have concerns for their own body: "I get it, it could be…genetic, and so…I might have a gene." Some attempted to stay positive about how they would cope with a cancer diagnosis while others expressed this fear as "a real downfall" of having a parent with cancer. One 15 year old shared,

> I'm concerned about the possibility that I might get it, that it might be hereditary. I wouldn't like (getting cancer) and I would really try to think of a way to cure it to stop that from spreading to other people.

Some even alluded to the fact that the stress they were experiencing living with their parent's cancer for such an extended period of time would affect their health and make them more susceptible to illness.

> I realize that my health is kind of fragile, I worry about things like chemicals, and, and um, different stuff in food, and, oh, not getting enough

sleep. And…it just seems like I could get sick pretty easily. (15 yr old female)

Adolescents would watch their parents' pain during treatment while wondering if they would have to endure the same thing as adults. This left them feeling insecure and afraid,

I do think about it (getting cancer)...when I do think about it, its kinda scary cause I don't want my daughter to have to deal with it and I don't want to have to deal with it or my son. (14 yr old female)

1.4 Worrying about recurrence. The uncertainty and fear of relapse was yet another concern expressed by these adolescents. "I wanna know if she's gonna have (cancer) again cause she's had it two or three times now and how are they gonna deal with it better?" One adolescent explained that a recurrence was almost worse than death because they knew it would entail further treatments, hospitalizations, and stress for the family.

I worry about what would happen to me if she died? Or what would happen if she had a bad recurrence. In some ways that one's almost even worse because I know what would happen. She'd have tests…But then I don't know what would happen if she was hospitalized or something. (15 year old male)

Their memories of active treatment were traumatic. Their indeterminate future and anxiety about what was going to happen next always loomed in the background.

1.5 Things taking a turn for the worse. This level of uncertainty was reported as one of the most difficult parts of the advanced cancer experience. Anxiety about the future and the inevitability of the battle against cancer being lost permeated through all the adolescents' responses during the interviews. One 11 year old shared,

> I feel really bad cause my dad won't live as long as other dads will. I worry when my dad is gone I'll really miss him, and when everyone else has dads and I don't it will be really depressing.

Another adolescent echoed this feeling, "It's like my regular mom but the cancer it just keeps on making me think about how she's going to go away. Like, leave me and I don't want her to leave me."

These adolescents regularly thought about death in connection to their parent's illness and assumed their parent would die sooner or later even if this had not been directly communicated. A repeated theme of the ill parent leaving, dying, not being there for them in the future and a fear of sudden loss was apparent in their responses. This 13 year old expressed what made cancer difficult, "just being concerned if anything takes an immediate wrong turn, for the cancer, if he suddenly goes into, a stroke or a heart attack." One adolescent felt as if their family was living on borrowed time, "The idea that (mom) might die is hard for me. I mean I know she could die anytime, and….she could have (died) years ago, so I feel lucky."

These adolescents in a sense were already grieving the perceived lack of future they had with their ill parent.

So that's the one thing I'm really worried about is that she's not going to be there for me a lot. I think about like when is she going to leave me? And who I would be staying with? I wonder is she still going to be there for me when I graduate. (13 yr old female)

They were grieving the loss of their parent being able to see them reach milestones such as graduating high school, going to college, and having kids of their own.

1.6 Worrying. The daily worries and concerns about the cancer were present yet distinct from the larger worries about the future and death. Nonetheless, they had a meaningful impact on the adolescents' lives. When asked what worried them about their parent's cancer they responded with the following:

I worry mom gets stressed out a lot. You know, every day, like, if she doesn't get enough sleep or if the house is messy, or if she thinks dinner isn't very good, just, yeah, she seems (to worry) a lot. (15 yr old female)

Well, kind of that more grim outlook on life, kind of (causes me worry).In some ways I wish she wasn't like that. (15 yr old male)

These adolescents' were keenly aware of their parent's physical and emotional state and reported concern when parents seemed stressed, physically ill, tired, or sleeping too much. As one adolescent offered, "I worry mom is really stressed out or not feeling well like just tired or even like physical sickness." Another 13 year old explained, "Like (mom) throwing-up worries me and when she's not feeling good and she's just laying in

bed." They felt sad that their parents were deteriorating in this way. Adolescents reflected on their worries, "Sometimes I just think I worry a little too much about it (cancer), I get all like sad when I could be having fun with dad." Overall, it left them with a disturbing unsettled feeling that nothing was ever totally normal in their lives.

Domain 2: Cancer changing everything

Cancer impacted every aspect of their family and these adolescents' responses exemplified the fact that when one person in a family is diagnosed with cancer it deeply impacts the lives of every other person close to them. The family system was forever changed by the parent's cancer diagnosis. The role of each member was redefined as the ill parent was transformed physically and emotionally. The adolescents spent the majority of their childhood on a different path that now included cancer as a permanent part of their lives. Adolescents' clearly expressed how cancer and, in particular its treatment, disrupted their entire family's way of life.

2.1 Taking their energy away. The adolescents' vision of cancer and cancer treatment focused on the significant amount of fatigue experienced by the ill parent. When asked to describe cancer most adolescents described their parent's lack of energy, constant napping, resting, and staying in bed. As illustrated by the following quotes, "She has to take naps, it, (cancer) just kind of limits what she can do." , "She doesn't have a lot of energy, so she needs to take a nap and that means that I need to be quiet and just kind of not make any noise", "She got home from chemo, she was always tired and looked like

she just was sick and she would be in bed for a while, basically it's like she had the flu every other week." and, "I (picture cancer) as mom in her bed, laying down, sleeping."

The definition of cancer became synonymous with taking their energy away. As this teen articulated, "Cancer is this thing that takes her energy away. More the treatment than the cancer I suppose…she is in bed a lot, takes naps in the afternoon, I get home and she is still in bed."

2.2 Having a grim outlook on life. Adolescents also remarked on the toll cancer took on their parents emotionally. They felt at times their parents were worried, stressed out, or being pessimistic when they spoke of planning for a future without them. As this 15 year old perceived, "(Mom) has more of a grim outlook on life. One example is like she talks to me about what would happen if she died." Another adolescent described her ill parent, "She gets stressed out a lot. If she doesn't get enough sleep or if the house is messy, or if she thinks dinner isn't very good, just, yeah, she seems to worry a lot." They also noticed mood swings and at times felt their parent was upset with them. As one 13 year old shared, "When he wakes up from a nap he'll be real cranky and sometimes he'll be real nice… Sometimes he'll have mood swings." Another offered, "It's (hard) having her be in bed not as active as she usually is and not upbeat."

2.3 Putting up with a lot. These adolescents' were able to understand their parent's perspective and realized the cancer experience was a lot for them to handle. They were also capable of empathy for the ill parent's pain and physical discomfort. They would describe the pain, "She tells me that it's in her stomach and it hurts a lot and

she has to have surgery a lot and (cancer) doesn't make her feel good" and, "Dad has more hot flashes; he's taking A LOT more medicine." They recognized that the cancer was exhausting both physically and emotionally and appreciated the ill parent's efforts. As this 15 year old stated, "Well she has to eat differently, she has to go to the doctor a lot, (cancer) is hard for her." Another reflected, "She (mom) probably tries hard to make it that way…cancer in the background (for kids) because she does have to do a lot, and put up with a lot." They try to be accepting of their parent's journey as well and reflect on how their behavior affects the ill parent. As shown in this comment, "I have lots of attitude with my mom. And on top of that (cancer) she has to take care of and then like on top of that she um, is worried about me."

2.4 Growing up with parent's cancer. For these families advanced cancer was not a rapid illness progression but a long process of relapse, remission and ongoing treatments. These adolescents' explained that cancer had been a part of their lives since they were small children, "She's had (cancer) for a long time…So, I've pretty much grown up with it." Cancer has been an ongoing part of their lives, "He was diagnosed when I was like, a year, because, his tumor was like 10 years ago. I guess I wasn't old enough to realize what was going on." Many expressed difficulty in remembering what their lives were like before the parent had cancer and therefore it was difficult to differentiate if their relationships with their parents, friends etc. have been "changed" due to the cancer because for them the cancer had always been there. As one 15 year old explained she noticed her mother had less energy, "She's had (cancer) for a long time, so I don't know, she had more energy when I was five or six but she was younger too, so I

don't know, it's both, probably." It becomes difficult to distinguish changes in their lives due to cancer because cancer has developed into a backdrop for their entire childhood.

2.5 Parents not being able to do as much for me. The adolescents' are able to compare their families to their peers and notice differences in their daily lives and routines. Their parents could not provide as much logistical support as they desire. This may include driving them to and from school, helping with homework, participating in extra curricular activities, or even just having the time to talk. The following quotes exemplify this experience:

> She (mom) can't do as much for me like I take the bus home everyday I'd prefer to be picked up. She has less energy for extra-curricular stuff. She can't drive me places. (15 year old male)
>
> My schedule is overwhelming with soccer, Tae Kwon Do…and homework. It would be too much of a rush for them (parents) so they worry about me, if um; they are just doing too much or too little. (13 yr old female A)
>
> Sometimes just getting through school, it can be a little challenging in that sometimes when no one can help me. (13 year old female B)

Cancer clearly adds an additional burden on these families that ends up taking time away from their normal family activities.

2.6 Doing more to help out. The adolescents' do attribute having more household responsibilities due to the parent's cancer. They are asked to help out more with chores, cooking, and cleaning; "I clean the house on Saturdays.", "It's hard that she asks me to do more than my friend's do" and, "She wishes I would vacuum more. I

know it's hard for her to carry that huge vacuum around." They seem to understand that the healthy parent is often working or taking care of the ill parent and the ill parent does not have the energy to complete these tasks. In general these adolescents' did not seem to mind taking on these responsibilities but did point out that it was frequently more than their peers were asked to do and sometimes interfered with their outside responsibilities such as school and extra curricular activities.

> Sometimes it's kind of annoying when (mom) asks me to make a sandwich. I'm willing to do it, but especially like, when she's asked me to do stuff when I'm in the middle of my homework. (15 year old male)

> Sometimes I have to keep my brother entertained you know cause my dad was busy with my mom. (14 year old female)

They also realized that the increased demands were inevitable and they did not place blame on their parents or the cancer. Some even seemed to appreciate the opportunity to provide tangible help to their ill parent. As one 15 year old explained, "At home I think about ways of helping my dad like helping him with tasks and stuff making it easier for dad."

> Sometimes I help around the house (helps me feel better about her cancer). Sometimes, not all the time. Yeah, because my mom usually has to do all the work by herself. (13 year old female)

2.7 Taking care of my parent. Caring for the ill parent physically was not a responsibility that many of these adolescents had to deal with. Only a few of the teens

reported having to care for ill parent after surgery or treatment and most of those tasks were minimal such as getting a glass of water or making a meal. One adolescent felt caring for her ill mother was an expectation, but most noted that their parent "wanted them to care about them but not do things for them."

Caring for the parent by providing emotional support was more prevalent. Adolescents' accomplished this by talking and listening about the parent's concerns, comforting the ill parent, and "providing moral support". They also attempted to shield the ill parent from any additional stress by being quite and not mentioning or "bringing up bad topics when (their) not in a good mood."

Domain 3: Strategies – I don't like middle ground, either directly confronting it or going away

Strategies the adolescents used to deal with their parent's cancer varied greatly and each adolescent seemed to use more than one strategy to manage the cancer. Some would fluctuate between trying to get away from the cancer and addressing the fear or concern straight on. Most of them described the support they received from outside of the family as minimal. Adolescents seemed to swing between avoidance of home and leaning in to increase family time. This 15 year old explained it perfectly, "Either directly confronting it (the cancer) or going away helps me. I don't like middle ground." Another answered this question, "When things get hard because of your parent's cancer what do you do that helps? I either don't think about them at all or talk about them." One adolescent offered,

> My friends just cheer me up, like they'll play with me and say, like, 'don't think about (cancer) that much.' They'll talk to me about (cancer), and they'll just say, 'it's going to be okay and we'll be there for you when…he (dad) is gone.' (13 year old female)

3.1 Trying not to think about the cancer. Many adolescents' purposefully tried to put the cancer out of their minds as a strategy to make the experience easier for them. As one teen shared, "I try not to think about mom dying. It wouldn't help to just….keep…thinking about it." Another offered, "Just not think about cancer and have fun while dad's still with us. I just think to myself, well forget about it for now, just be happy he's there." They admitted they were not always successful but if things got too hard or too overwhelming they often just put everything out of their mind as a way to protect themselves.

> What makes cancer easier for me? Well, I don't think about it a lot so I don't have to deal with it as much. Well, not thinking about cancer is how I deal with it, I suppose it's purposeful. (15 yr old male A)

3.2 Trying to stay positive and calm. Being positive, optimistic about the future, and happy in the present moment was a strategy used by these families. This was achieved by enjoying time playing with the ill parent and not dwelling on the negatives of cancer. No matter how dire the situation, human beings need hope to survive and these families are no different. They were not able to live in a constant state of crisis and reality of the hopelessness of the disease. Parents sometimes offered reassuring words, "Mom tells me she is not going to die, she has the will to live," and "dad says everything

is going to be all right." Adolescents were comforted by parents' positive attitude, "Mom tries not to talk about cancer as if it's a really terrible thing, you know, it's just an annoyance, and it's not nice, and it's not good, but…but she doesn't dwell on it too much," and "Mom doesn't complain about (cancer)." All families used this response in some way; it seemed to be a universal coping technique. These adolescents felt focusing excessively on the cancer would not help the situation. As one 13 year old female shared, "Just keeping positive (makes cancer easier) like being happy, I'm trying to stay positive and calm when the cancer gets real serious."

3.3 Playing when things get hard. Some of the adolescents' chose to actively escape or avoid the cancer by participating in fun activities. Reading books, running, playing soccer, video games and hanging out with friends all were identified as ways that helped them get away from the cancer. As these quotes illustrate, "I just go off and do homework or, play games or go running with my running buddies" and "(When things get hard) I probably read a book or hang out with my sister…we'll talk or have a lot of fun, play with the neighbor kids."

3.4 Talking about hard things helps me. Five of the adolescents felt talking about difficulties helped them feel better. The cancer experience was easier when they were able to communicate with their family and friends. "My friends will cheer me up, and talk to me about (cancer) that helps," and "It helps to talk to my friends about what's going on with mom." They appreciated that cancer was not a taboo topic in their home even if they didn't talk about it all the time. As this adolescent explained, "Mom talks

about it (cancer). It's not taboo. We talk about like what treatments she's going through, what they're doing next, what the test results were."

3.5 Spending time together. Spending more time with family physically and emotionally was used as a strategy to help the teens deal with the difficulties of their emotions and circumstances. One adolescent explained, "When I'm worried about something I just go cuddle up with my mom." Some felt an urgency to spend time with and enjoy the parent while they were still alive. As illustrated in the following remarks: "If like, today would be his last day of living, um, just to spend as much time as possible," and "We (family) just think we should just have a good time while dad is still here. Helps to have fun while dad is still with us."

Being able to have intimate moments was another aspect of this category. Sharing times when the family could just be physically close to release sad feelings seemed to help.

> When she first told me (about the cancer)…I just laid there and cried with my mom and my sister. It was just all 3 of us just laying down. That's all we do cry… it helps because I'm right there with my mom and I'm not crying with someone else. (13 yr old female B)

3.6 Hanging out with friends. Friends were seen as a way to escape from the cancer and to get family problems off of their minds. One adolescent shared, "Hanging out, talking, going over to each other's houses, it all will get my mind off his cancer." Some adolescents stated they felt well supported by their group of friends. As one

offered, “I talk to them about it, they (friends) will actually think about and care about it (mom having cancer) ...yeah It’s nice.” According to the adolescents’, friends that were informed about their parent’s cancer routinely checked in about how their parent was doing. Some of their friends would offer advice: “(Friends) just say, like, ‘don’t think about it that much’- they’ll just cheer me up.” When peers were able to provide support it seemed to help a great deal.

Some adolescents’ expressed that their friends were not even aware their parent had cancer: ‘no one at school knows.’ One adolescent shared her desire to have closer friendships: “I do think I need closer friends because I don’t really have close friends. So I don’t really talk with any of them.” Another claimed that her friends were not equipped to offer the support she needed: “When I go talk to my friends……and I tell them…..they don’t really understand to have a parent with cancer….Mostly because I talk to my friends about almost all my problems and they don’t know what I’m really talking about.” Adolescents’ seemed to seek peer support but it was not always available or adequate.

3.7 Getting support from others. Adolescents’ identified other resources for information and support related to their parent’s cancer such as the internet, school teachers, and their parent’s adult friends. Adolescents’ also shared that their parent’s made some effort to get support for them outside of the family: “Mom has taken us to go see counselors,” and “mom encourages me to go see the school counselor. Mom wants like a support system (for me).” These adolescents’ did not typically view counselors as

helpful or the counseling was initiated early on at the time diagnosis and was not continued as the cancer advanced.

Domain 4: Talking about it

Adolescents had different views on the desire and frequency of family discussions concerning their parent's cancer. Their rationale for having open communication, or not, included factors like the length of the illness, age of the children, and fact that cancer was an inevitable part of their lives that they had to discuss at some point. Sharing information about treatment and doctor's visits, among other issues, were most common. Most adolescents expressed a desire to be kept updated on medical information about the cancer and identified their parents as the people they could use as a resource if they had questions about the cancer. However, this did not always translate into comfortable communication about the emotional aspects of their experiences. According to one adolescent, she never initiated conversations about the cancer because her parents, "We're already overwhelmed and tired of talking about it."

4.1 Talking about hard things makes it easier. Some of these adolescents' said talking about the cancer with their parents helped make difficult situations easier for them. They felt their parent was receptive to their concerns. These parents' openly shared feelings and checked in often with their children about the cancer. These adolescents' did not identify many obstacles to communication with their parent, as evident in the following responses: "He'll just come home from the (cancer treatment

center) and he'll either be happy or, 'oh this happened' He shares information with everyone either way."

> Like other people's parents, I know that they'll be having their parents be having cancer and they don't really talk to their moms about it and stuff. I talk, I talk to her about (cancer), like talk to her-talk to her...and it helps. (14 yr old female)

4.2 Not saying much about cancer. Some of the adolescents described their families as lacking the desire or need to talk about the cancer: "Dad and I usually don't talk about it" or "Dad rarely talks about his cancer." They reported parent's not sharing new information right away or recalling not even being told about the cancer as young children. One adolescent shared, "I didn't even know it was cancer the first time. Mom didn't tell me."

In some ways these adolescents felt that cancer had been such an ongoing aspect of their lives that it no longer needed to be discussed: "It's (cancer) is kind of at the back of my mind, and…I mean, I worry about (mom) sometimes, but…it's not like every time we talk to each other that (cancer) is the first thing I think of."

Another adolescent offered this reason for limiting her discussions about the disease.

> Well, I know moms already, she's tired of (talking about cancer), she doesn't really want to talk about it a lot probably, because she talks to all of her doctors, and she talks to her parents about it, so I don't feel like I need to talk to her a lot about it.

4.3 Talking about cancer is hard. Several adolescents managed to elaborate further and reflect on their lack of communication. They admitted avoiding the topic because it was scary: "I guess my own fears, death really…stop me from talking about it." It was difficult for adolescents to initiate these difficult conversations. As one shared,

> It's really hard (to talk to dad about cancer) but yeah, I usually don't talk to (dad) about it. Well when I do talk to him about it (cancer) it's a little hard for me to get the courage to ask him.

Even though cancer was at the back of their mind some adolescents explained how they avoided talking about their parent's cancer because it was painful: "I don't talk about it that much, I don't talk about it like in front of them, because it just makes me feel sad, bad."

Domain 5: Cancer was a positive for me…it taught me

Many of the adolescents were able to describe positive aspects of their family's cancer experience. They reflected on lessons they had learned and aspects of their character that in a large part were due to the fact that they experienced this challenge in their lives. In a way cancer helped shape these young people into emerging young adults influencing their self image, maturity, and perspective on life.

5.1 Being self reliant. A consequence of having a parent with cancer included increased household demands and less availability of both parents. Adolescents' shared that this enabled them to become more independent: "I think in the end (mom's cancer) was positive for me. Mainly because it taught me two things: It taught me how to take

care of myself and not be reliant on other people." These adolescents were confident in their ability to meet their own basic needs as some shared, "I make my own dinner", "I can do my own laundry," and "I can clean this entire house by myself," as a result of their parent's illness.

5.2 Knowing a lot more about cancer. According to some adolescents, they acquired more medical knowledge as a result of their experience: "I know more about like cancer and illness." Another adolescent reflected, "I've thought a lot more about cancer and how it affects people. I have learned more about cancer than I used to know." As one teen noted this may lead to a desire to enter the medical field, "Well I know about (cancer), I know my dad has cancer so…I can possibility help find a way maybe when I am older to stop cancer."

5.3 Obsessing about staying alive. Having a parent with cancer led some of these adolescents to lead healthier lives by being more aware of their own health: "I probably eat healthier food than (mom) did." Another shared how he felt healthier than his peers,

> I guess I'm more aware of health, things like risks. I'm more aware of how to be healthy and….a lot of other people at school they don't seem to think about that at all. They just eat anything and they don't really seem to care. (15 yr old female)

These adolescents' cancer experience led some to take a proactive approach to staying healthy, as a way to have some control over their situation.

> I'm just kind of excessive about it. I mean I wasn't going to do them anyway, like I would not do drugs or anything, but I definitely wouldn't do them because they shorten your life.…I'm kind of obsessive about staying alive. In a way that I wouldn't be normally. (15 yr old male)

5.4 Preventing me from living in a dream world. The maturity of these adolescents was evident in their ability to reflect on their lessons learned: "Cancer taught me life is going to end, life…it's not exactly long," and "I don't take things lightly." Another adolescent shared how having a mother with advanced cancer,

> Leads to self-reflection, I suppose. Well, in a way you sort of start looking at your own life. Because there's a possibility that you're mom's going to die soon. Um, so you look at your own life, you look at what, what happened to you, you look at what would you do if that happened? (15 yr old male B)

They seemed to accept the reality of their situation and appreciated their understanding of mortality.

> Well it sort of prevents me from living in a dream world of like, "Oh yay, everything's cool" you know. I mean that may be debatable, whether it was a good thing or a bad thing. But that's what (cancer) taught me. (15 yr old male A)

5.5 Always being there for me. Cancer increased these adolescents' happiness for their family, in particular their relationship with the ill parent. When describing positives from the cancer, they shared how appreciative they were of the time spent with

the ill parent: “Well he’s always there for me, He’s always there to help me,” and “That (mom’s) there for me and that I know she’s not going to leave anytime soon.” Another adolescent offered, “He (dad) does spend more time with us a lot, and he’s really outgoing and really nice to us.”

Cancer created reasons to have more quality time, share rituals, take time to talk, and grow closer as a family. As one noted, “I’ll just sit there, watch TV with my family. It can be fun,” and “It is fun how we hang out as a family.” Taking advantage of the time they had with their ill parent was important as described by this adolescent, “One day would be his last day, and to spend as much time with him as possible.”

Adolescent’s Psychosocial Adjustment

In addition to the qualitative interviews, adolescent’s completed standardized measures of behavioral and emotional adjustment, self esteem, anxiety, and parenting quality. The measures used included the CBCL, YSR, RSE, and STAI.

The average total score on the CBCL was 45.57 (SD=13.13) with a median score of 43. Only one child measured above the clinical cut off for the CBCL total scale (>60), with a total score of 66 falling into the aggressive and delinquent subscales of the CBCL. On the YSR the adolescents scored within the normal range (M=47.14, SD=6.23). Most of the adolescents also scored with the normal range on the STAI with total scores ranging from 24-44 (M=31.43, SD=6.85). One adolescent scored above the clinical cutoff for the STAI (>39), with a total anxiety score of 44.

The range of scores for the RSE self esteem scale was 10-27 (M=16.14, SD=6.07). The RSE scale allows for scores ranging from 0-30 with 30 indicating the highest score possible.

Discussion

Researchers and clinicians have insufficient data on which to characterize the adolescent's experience with a parent's advanced cancer and are currently unable to develop evidence-based interventions to assist the adolescent and ill parent. Currently there is a lack of literature documenting the adolescents experience with non-curable cancer in a parent and how they manage the cancer's impact. This study directly addressed these gaps in knowledge and found that these adolescents worked to weave the cancer into their lives in a way that allowed for some sense of normalcy despite the inescapable impact of the illness.

These adolescents showed a significant amount of worry and anxiety due to their parent's advanced cancer, particularly when the ill parent showed physical symptoms such as fatigue or psychological distress such as negative affect or mood swings. These results were consistent with previous research indicating parent's physical health and mood had significant impacts on adolescents' emotional adjustment (Kennedy & Lloyd-Williams, 2009; Siegel, et al., 1996a). Another significant source of distress reported by adolescents was fear of impending death of their parent and concerns for their own health due to possible genetic links of many cancers (Beale, ESTELA A, Sivesind, DEBRA, & Bruera, EDUARDO, 2004; Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). The adolescents in our study reported persistent fears about the future including: that "things

could take a turn for the worse" and their parent would die from the disease, or anxiety about the possibility of getting cancer themselves. Furthermore, our results mirrored previous findings indicating adolescents' increased chores and household workload due to their parent's lack of time and energy for meeting these needs (Christ, et al., 1994; Grabiak, et al., 2007; Kennedy & Lloyd-Williams, 2009). However, in contrast to other studies of parental cancer, adolescents in our study reported minimal direct care giving responsibilities for their ill parent although emotional support was expected (Grabiak, et al., 2007; Spira & Kenemore, 2000)

Previous research has shown the terminal phase of a parent's illness may be a period of great psychological vulnerability for children and adolescents (Siegel, et al., 1996a). Our findings reflect this as well as shed light on how families managed when the "terminal phase" of cancer stretched on for many years, encompassing a significant amount of these adolescents childhood. Adolescents shared how they and their families used strategies such as staying positive, not thinking or talking about the cancer, and engaging in diversionary activities in order to create a sense of normalcy in their lives. This need to maintain normalcy was also reported in studies interviewing parents with advanced cancer (Bell & Ristovski-Slijepcevic, 2011; Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; Turner, et al., 2005). Parent's felt a sense of responsibility to protect their children from the impact of cancer by sustaining routines and not regularly communicating about the illness (Bell & Ristovski-Slijepcevic, 2011; Kennedy & Lloyd-Williams, 2009). These tactics worked to a degree but most of these adolescents reported being acutely aware that their time with their ill parent was limited. Similar to Sheehan

& Drauker's (2011) findings, adolescents reported a sense of not having enough time together and were determined to make the most of the time they had left with their parent. As a result being able to spend time with their ill parent and family unit became an important coping strategy similar to other studies (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). An additional positive aspect of the advanced cancer experience found in our study and consistent with past findings was the adolescents increased independence and self reliance (Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011).

Most of the adolescents in our study described either themselves and/or their parents as having a closed communication style in regards to the cancer. Although this led to an interim sense of normalcy, this avoidance seemed to also create a feeling of isolation and a lack of perceived support for the adolescent. The adolescents that reported minimal communication about the cancer also struggled to make meaning out of the cancer experience and were most likely to feel alone, powerless, and like the weight of the world was on their shoulders.

The results from this study can be used to inform both future research and clinical practice. Health care professionals should assess families' communication styles and provide support and encouragement for parent's to integrate regular opportunities for expression of thoughts and feelings related to the cancer experience. HCP's should also facilitate family interventions that provide parents and adolescents a venue to process the impact of cancer on their lives. This may allow for opportunities to reframe the cancer experience and find positive meaning from their challenges. The development of

programs to meet the needs of families living an advanced cancer diagnosis must be support and informed by more research identifying important factors to consider for this population. Quantitative and qualitative studies are needed to examine long term outcomes by using longitudinal designs to describe families' needs at different points of the illness trajectory. In addition, as our study's quantitative results suggest measures of clinical levels of psychopathology may not provide accurate depictions of the challenges this population face. An assessment of the adolescent and family's quality of life may be more sensitive to the impact of cancer on their lives.

This study's results are limited to a primarily Caucasian, well educated sample of married couples and their children. Thus future studies should attempt to include larger, more diverse samples of families dealing with advanced cancer.

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Table 3.1 Weaving a Normal Life with Cancer: Domains and Categories of the Explanatory Process

Domain 1: Feeling the Weight of the World on My Shoulders
1.1 Not being able to make the cancer end
1.2 Feeling alone.
1.3 Getting cancer would be a real downfall.
1.4 Worrying about recurrence
1.5 Things taking a turn for the worse
1.6 Worrying

Domain 2: Cancer Changes Everything
2.1 Taking their energy away
2.2 Having a grim outlook on life
2.3 Putting up with a lot
2.4 Growing up with parent's cancer
2.5 Parents not being able to do as much for me
2.6 Doing more to help out
2.7 Taking care of my parent

Domain 3: Strategies – I don't like middle ground, either directly confronting it or going away
3.1 Trying not to think about the cancer
3.2 Trying to stay positive and calm
3.3 Playing when things get hard
3.4 Talking about hard things helps me
3.5 Spending time together
3.6 Hanging out with friends
3.7 Getting support from others

Domain 4: Talking about it
4.1 Talking about hard things makes it easier
4.2 Not saying much about cancer
4.3 Talking about cancer is hard

Domain 5: Cancer was a positive for me…it taught me
5.1 Being self reliant
5.2 Knowing a lot more about cancer
5.3 Obsessing about staying alive
5.4 Preventing me from living in a dream world
5.5 Always being there for me

Table 3.2 Adolescent Interview Schedule

1. In your own words, describe your parent's cancer.
2. What do you think caused his/her cancer?
3. What questions do you have about his/her cancer?
4. How do you want your parent to share new information with you about the cancer?
5. What information do you want about the cancer that you still don't have?
6. If you have questions about your parent's cancer where do you go?
7. What changes if any have you noticed in your parent because of the cancer?
8. What things do you notice about your parent if anything that causes you worry or concern?
9. How do you think your parent's cancer's changed your life if at all?
10. What if anything is difficult about having a parent with cancer?
11. What has been a positive for you about having a parent with cancer?
12. Is there anything that you do particularly when you're worried or feeling badly that helps you to feel better?
13. What if anything do you do that makes it easier to have a parent with cancer?
14. When things get hard because of your parent's cancer what do you do that helps?
15. How has your parent's cancer changed things with your friends if at all?
16. What if anything do you do with your friends that helps you with your parent's cancer?
17. What if anything do you think about the possibility of getting your parent's cancer?
18. What concerns if any do you have about your own body because of your parent's cancer?
19. What things are you asked to do now(to help), since your parent's cancer, that you don't mind doing?
20. What things are you asked to do since your parent's cancer that you don't like doing?
21. How if at all are you expected to help care for your parent?
22. How has cancer changed your relationship with your parent, if at all?
23. What if anything does your parent say that helps you with his/her cancer?
24. What if anything does your parent do that helps you with his/her cancer?
25. What if anything does your parent do that makes things harder for you with her cancer?
26. What if anything does your parent do that makes things easier for you?
27. What if anything do you need from your family, or from your parent that you don't get.
28. How is it to talk to your parent when you have a concern or worry about the cancer?
29. What if anything stops you from talking to your parent about the cancer?
30. How often at all does your ill parent check in with you to see how you are doing?
31. How often if at all does your parent check in with you about the support you are getting because of the cancer?

32. What if anything has your parent done to help you get support for the cancer outside the family?
33. Is there anything else you want me to know about your experience with your parent's cancer?

Chapter 4

Life interrupted: The lived experience of adolescents who have a parent with advanced cancer

Abstract

Adolescents are considered to be the group most susceptible to negative psychosocial outcomes when faced with a parent's illness. Yet, there has been extremely limited research on the adolescent's adjustment to advanced parental cancer. The aim of this study was to gain understanding of the experiences of these adolescents in their own words to gather pilot data on the needs of this population that will be valuable in developing interventions for adolescents facing parental cancer. A hermeneutic phenomenological approach was applied using in-depth, semi structured interview methodologies to inquire about the adolescents experiences. Ten adolescents (7 males, 3 females) aged 14- 17 were interviewed. Four essential themes about adolescents living with a parent's advanced cancer emerged from the analysis: *Life interrupted, Being there, Managing emotions, Positives prevail.* The findings in this study underscore the significant impact an advanced cancer diagnosis can make on a family system and suggest that the experience may also have the potential of creating opportunities for growth and well being. Our findings reinforce previous results that advocate the importance of family and peer support, positive attitude, and open communication when a family is coping with advanced parental cancer. Understanding how adolescents gain strength from their relationships with family and peers offers healthcare professionals an opportunity to have services and strategies in place to foster these relationships.

An estimated 2.85 million children in the United States are living with a parent who has been diagnosed with cancer (Weaver, et al., 2010). Moreover it is estimated that close to 55,000 children may experience the death of a parent from cancer each year in the United States (Weaver, et al., 2010). Children and adolescents facing the death of a parent from cancer constitute a vulnerable population often overlooked by health care professionals (HCP), and researchers.

Adolescents are considered to be the group most susceptible to negative psychosocial outcomes when faced with a parent's illness (Grabiak, et al., 2007). Yet, there has been extremely limited research on the adolescent's adjustment to advanced parental cancer. Prior to the conduct of the current study, existing research that involved the experiences of families with a parent diagnosed with advanced cancer were analyzed in the literature. There was paucity of research on the adolescent's experience when a parent has advanced cancer with only 7 studies identified that focused on the impact of children and adolescents faced with a parent's advanced cancer. These studies suggest adolescents' living with a parent's advanced cancer show significantly higher levels of distress, anxiety and depression as well as lower self esteem than their peers (Rainville, et al., 2012; Siegel, et al., 1996b; Siegel, et al., 1992). In addition, parents reported higher behavioral problems and lower social competence in the children with a terminal parent (Kennedy & Lloyd-Williams, 2009; Siegel, et al., 1992). Possible factors that impact the adjustment of adolescents to their parent's advanced illness included poor parenting, open

communication style, age (early vs. late adolescence), and the parent child relationship (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009; Rainville, et al., 2012; Sigal, et al., 2003). These findings suggest the end stages of a parent's illness may be a particularly vulnerable period for adolescents.

The prevalence of positive well being is rarely addressed in the literature on parental cancer. However, in the case of advanced cancer, positive aspects of the cancer experience seem to consistently emerge from the findings. Several of these studies have found, at times unexpectedly, evidence of resilience or protective factors that have led to a positive outlook for these families despite their many challenges (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011; Sigal, et al., 2003).

It is important for health care professionals to understand how adolescents experience difficult life circumstances to better meet their psychological and emotional needs. Currently, interventions provided by clinicians to support adolescents dealing with advanced cancer of a parent lack any empirical basis in the literature (Muriel & Rauch, 2003 & Foley, Back, Coyle et al, 2005). There is little knowledge on how adolescents handle living with a parent with advanced cancer. A critical task in the beginning stages of this research is to ask the adolescents themselves. The aim of this study was to gain understanding of the experiences of these adolescents in their own words to gather pilot data on the needs of this population that will be valuable in developing interventions for adolescents facing parental cancer.

Method

Study Design

The theoretical framework that guided this study was based on the Resiliency Model of Family Stress, Adjustment, and Adaptation, a stress and coping framework based on a family systems approach (McCubbin, et al., 1996). This strength based framework assumes the experience of families facing a crisis such as advanced cancer is normative, not pathological and has the potential to be buffered by resilience factors. This qualitative study used in-depth, semi structured interview methodologies to inquire about the experience of living as an adolescent with a parent who has been diagnosed with advanced cancer. Qualitative methods have been shown to be effective as preliminary research with understudied populations (Miles & Huberman, 1994). In addition, qualitative methods are especially well suited to the development of thick data about families and human development (Daly, 2007). Hermeneutic phenomenology was the approach chosen because the researchers wished to obtain a description of these adolescent's experiences and this method provides the richest and most descriptive data (Creswell, 2007). The phenomenological approach allowed us to capture the common experiences of this group as it was understood by the adolescents themselves.

Sample

After study approval by the institutional review board at a southwestern university, criterion sampling was used to identify participants who met the inclusion criteria. Families were informed about the research project by a community based non-

profit that provides psychosocial support for families facing a parent's life threatening illness. Interested parents and adolescents were then contacted by the researcher. The project was described, questions were answered, and the adolescents were invited to participate in the study.

The study's participants met the following inclusion criteria: (1) adolescents aged 12-18 years at time of interview; (2) currently living with a parent diagnosed with advanced or metastatic cancer Stage III or above; (3) English speaking. Exclusion criteria: (1) parent with cancer is no longer living; (2) adolescent does not live in the same household as the ill parent at least 50% of the time.

It is important to note that all of the families recruited for this study were involved with the same agency which provides interventions for families experiencing a parent's serious illness. The agency aims to increase family communication and enhance the positive coping skills utilized by their clients. The majority of the adolescents in our study (8 out of 10) participated in individual or group support for their parent's cancer at a very young age (6-10 years old) when their parent received their initial cancer diagnosis. Although it is not within the scope of our study to evaluate outcomes of this intervention, it is possible the family's involvement in these services affected their long term cancer experiences.

Procedures

Ten adolescents living with a parent diagnosed with advanced cancer participated in this study. This article describes the qualitative results acquired from in-depth face-to-face interviews with these adolescents. The adolescents were informed that this study

aimed to learn about the experiences of adolescents dealing with parental cancer with the hope to create interventions to help other youth in similar situations. Adolescents were informed how their personal story would assist researchers and clinicians improve their work with this population. It is important to note that many of these adolescents were able to candidly and in great detail discuss their experiences with the desire to help other adolescents. Detailed demographic information can be found in Table 4.1. After signed consent was obtained, interviews were conducted with the adolescents using the attached interview guide (Table 4.5). The interview guide was adapted from a previous study by Lewis and colleagues (2003) and developed to elicit thick descriptions from participants. The researcher is a child life specialist with extensive experience working with families in many medical settings including work with children and adolescents who have an ill parent. Semi-structured interviews took place largely in the family's home or another convenient private location identified by the adolescents. Interviews lasted an average of 45–60 minutes and were digitally recorded. The recordings were transcribed verbatim. All transcripts were reviewed for accuracy before being entered into Atlas ti. 6 software.

Data Analysis

The researcher used a combination of the various approaches to phenomenological analysis as described by Moustakas (1994). Organization of data began when the researcher carried out a naïve reading and studied the entirety of the data including all transcribed interviews. However, the researcher's position as a clinician involved with this population and agency cannot be ignored and was addressed through adhering to the phenomenological procedures of writing assumption statements,

bracketing, writing field notes throughout the analysis process, and peer review. Prior to performing the interviews, the researcher recorded a list of assumptions about the population being studied in an effort to address the research with a "fresh perspective" (Creswell, 2007). Analysis began by listing every expression relevant to the cancer experience (Moustakas, 1994). As the researcher gained an overview of the participants' experience, the data was reduced by listing all statements and eliminating those that were repetitive, vague or overlapping. This process allows the researcher to obtain the meaning units or invariant constituents (Moustakas, 1994). These meaning units were then clustered or categorized into themes. The researcher uncovered common threads or concepts that linked participant experiences together in order to create these themes which were again reduced by removing overlapping or repetitive statements. The themes were validated by checking them against the complete transcriptions, making sure they were either explicitly expressed or compatible. The reliability of the themes were assessed through peer checking using a panel of experts on qualitative methods (Padgett, 1998; Rolfe, 2006). In hermeneutic phenomenology, validity refers to the fact there are no internal contradictions within the study (Armour, et al., 2009). From the ten verbatim transcripts, significant statements were extracted. Table 4.1 includes selected examples of these statements and their formulated meaning units. Arranging these meaning units into clusters resulted in the 4 basic themes. Table 4.2 contains two examples of theme clusters that emerged from their meaning units. These validated themes were labeled as the core of the experience and were used to develop textural descriptions. The textural descriptions are considered "what" the participants experienced with the phenomena and

include verbatim examples from the transcribed interviews (Creswell, 2007). Next, the structural descriptions or "how" the experience happened was formed by reflecting on the setting and context in which the phenomena was experienced (Creswell, 2007). Finally, from the integration of the textural and structural descriptions into the meanings and themes of the experience the essence of the phenomena was constructed. This final synthesizing of the data and creation of a composite description of the lived experience for the group as a whole was the ultimate goal of this phenomenological study.

Results

Four essential themes and sixteen subthemes about adolescents living with a parent's advanced cancer emerged from the analysis: *Life interrupted, Being there, Managing emotions, Positives prevail.* All themes and subthemes will be discussed below and are summarized in Table 4.4

Theme 1: Life Interrupted

The majority of these adolescents describe "growing up" with cancer and explain how since "we have dealt with it for so long…it seems normal." Cancer interrupted their family's life trajectory and things will never be the same. Although they describe observations of the considerable effects of cancer on their family, they also treat the disease as an inevitable piece of their lives. An interruption they now, "just have to deal with." There was a certain amount of uncertainty and lack of control weaved into their present lives and how they viewed the future.

1.1 Perceptions about cancer. These adolescents reported having a firm grasp of what their parent's cancer was, often citing the correct medical terminology of the

diagnosis, treatments, tests, and medications. However upon further inquiry many misconceptions and unanswered questions were uncovered. The most common was the cause of their parent's cancer. Many responded with vague answers such as, "it's just one of those things you get like, you know you catch a cold." As reflected in the following quotes:

> I don't know just the disease got in her somehow from some exposure, she got to something. It could be anything that causes cancer. P2

> I mean, there's so many myths and so many different things like some people say, it's a air pollution some people say, it just shows up. In my opinion I really, I just like to think that it just showed up. P9

Other's had firm theories about causes of their parent's cancer such as not breastfeeding, using cell phones, genetics, or air pollution. Regardless when asked they all had lingering questions that remained unanswered such as "Why is it there? How do we get rid of it? Will it ever go away?, What is actually happening in her body?, How do the drugs work?, Genetics is so broad…I still don't know what actually causes it."

1.2 Struggling with the changes. Adolescents shared observations of the effects of the cancer experience on their entire family in particular on their relationship with their parents. They described the limited availability of parents, strained relationships, and physical and emotional changes in their ill parent.

Parents unavailable. The demands of the illness caused both the ill and well parent to be routinely unavailable to their children. They claimed their requests such as homework or play were ignored because, "one parent was always helping the other parent out with whatever was going on." This led to frustrations for some children noting

they did “not have a soccer mom that could drive you around.” But regardless of their reaction to the changes they all noticed this shift in care giving roles once cancer became part of their family’s reality. As reflected in the following quotes:

> Mom used to drive us to school every morning, then she would like pack our lunches, and then we would start having to have like people drive us to school and like someone would be bring us dinners and it was like just totally different. My mom and dad would be gone from the house a lot at nights when we would get home, and we would have someone like spend the night with us. P8

> It's harder like you don’t have a mom that like can do as much She can't like do as much for you so you kind of have to fend for yourself, and like there's a lot of parents that like make meals all the time. P5

> I don’t have a car so like if (mom’s) out somewhere with dad at the doctor's and I can't -- I can't go anywhere stranded at home, and it can be tough when you know parents were gone. I mean….stuff like sports your parents always, can't always come. P1

Some adolescents described a shift in their relationship with their ill parent that seemed unavoidable due to the progression of the disease, side effects of medication, and time constraints. This 16 year old described how his father’s brain tumor impacted their relationship:

> I mean we're pretty distant now because (dad’s) not the same person obviously. He's really confused and you know its like, you can't really have a serious conversation him because he can't always grasp it so it's kind of tough. P1

> Mom works full time and she's also has to deal with cancer so she can't do a lot of stuff, so that kind of, sometimes it can turn into like arguments and sometimes you don’t have enough time with her to just like talk about like how her days were like how our life is and that can be hard sometimes. You lose like touch. P5

Changes in ill parent. Adolescents shared all the physical and emotional changes brought about by the cancer and its treatment on their parent. They seemed

acutely aware of the pain their parent's were experiencing describing symptoms such as fatigue, "she's exhausted from it(cancer)", "she can't sleep but she lays in bed a lot.", and "you can tell she is sick..she has dark circles around her eyes." They also described other side effects such as being confused, losing hair, loss of memory, headaches, trouble speaking, difficulty moving around, and pain. As one teen shared, "(the hardest part) is like seeing her in pain and there is nothing you can do to help her." In addition, there were emotional and personality changes in the parents that adolescents reported as consequences of medication and surgeries. According to one adolescent, "I think she gets mad easily. I think it's like the pills or something she just acts more mean." As seen in the following statements:

> I mean my dad's changed a lot you know, after each surgery he's becoming…obviously you're going to be a different person. I mean he's kind of gone through a lot of different moods I guess, and you know and he's been -- he's just changed. He's not the same person he was that I remember when I was six. P1

> (Mom) not understanding jokes at all or sarcasm, so when I try to be sarcastic and she thinks it's mean and she gets all mad, but that kind of stuff, small things. P10

1.3 Limits what we can do. Adolescents also reported that cancer limited what they could do as a family, time spent with friends, on school work and extra curricular activities. They described having to, "sacrifice doing something fun to stay home and help." As these teens shared:

> If I wanted to go over to friends, but my mom wasn't feeling well, I had to stay here with her, I couldn't go and all my friends out doing stuff and I had to stay here with my mom. P1

> I had to help out like especially around the time of her surgeries, like if she wanted company I'd have to not do what I had to do for school and

> then I sometimes skip dance classes too….because my dad still had his job too….and that was the harder part. P9

Some adolescents felt that family resources such as time and money were spent on the illness rather than the children.

> Maybe it's limited what we can do, like sometimes I can't go to certain places because she has to have an appointment to go to the doctors, so I think that's the only one, like it limits me on what I can do. P4

> Because of all the doctor bills I mean we're not that financially well off and I mean its kind of frustrating going to West Lake everyone has got a lot of money and we don't have any money because of my dad's expensive bills so I mean that can be pretty frustrating. P1

At times the adolescents were limited on their activities due to fears of infection while the ill parent was immuno-suppressed.

> I don't know why the real reason is, but she thinks that I'll probably get sick and I couldn't go to many one of those things(activities with friends), because I could get sick, and my mom can't -- couldn't like risk getting sick with like chemotherapy. P6

1.4 Voices of fear. All of these adolescents reported a certain amount of worry and anxiety related to their cancer experience. These included fear of their parent's health deteriorating as well as concerns for their own health. Some reflected on their fear of separation, "when I was really young it was hard for me to be away from my mom because I was always afraid something would happen to her." They described how it was, "hard…living with that uncertainty," about what the future would hold and an awareness that it was beyond their control. They described the cancer as, "unpredictable and vicious like everything else is going great in your life …but you have that one thing hanging over your head." Another elaborated:

> That she would die like just all of a sudden or just I don't know how far she is from death like it's just -- it's just the question of

> whether she would like how far away she is from it (death). It seems like it would be easier like it's harder to live with that hanging over your head than just to lose someone all of a sudden. P5

Adolescents shared how the experimental cancer treatments concerned them. They shared how their parent tried one drug after another and felt, “I don’t believe that because I know that can’t keep going on forever.” Another offered:

> We're so in the dark with science and cancer. There is not really a lot of things, I mean with my dad their just experimenting in everything like doctor like oh, let's try this, and we can't give you anymore surgeries, but we'll try this. So I mean it's just sad and they -- I don’t know if they have a full conscious realization of what's going on all the time you know they're doing their best. P1

Throughout these young people’s lives they had cancer lurking in the background and it, “tried to be the thing that’s going to stop your happiness almost all at once, but it doesn’t”. But the unease is never gone for long according to one teen:

> Well, just like overtime I just don’t even think about it (cancer) after a while because it just feels so normal… and then what's hard is when I started to think about it again because something like -- it feels like everything is going fine like and normal and then all of a sudden cancer jumps out in your face. P5

Moreover, the future remains uncertain for these young people as they share concerns they have for their own health such as, “am I prone to it(cancer)?” or “is there a recessive gene in me?”, and wondering, “is the overall long term stress, what’s it going to end up doing to me later on?” Another offered:

> I know that our family has a long line of history of, like a heart attacks… and when I hear that, then I start to think that, maybe our

> family also has a long history with the cancer that I don't know about and maybe like one of us could get it. P3

1.5 Juggling life and cancer. Adolescents described the added pressure cancer placed on their lives and, "The stress on the whole family". Cancer was, "a really trying thing" that made it hard to "just relax and live in the moment." They described the added responsibilities as one of the things that made cancer challenging. As these statements exemplify:

> The difficulty between like everyday issues and then like comparing it with cancer and stuff. I guess it's - it's hard to like get things done everyday when you still have that kind of in the back of your mind kind of juggling like life and then the cancer. P7

> It's harder as a teenager. Because you know more stuff about life, then when you are a kid, you basically have like no responsibilities and no worries, but then when you get to being a teenager, you have more responsibilities and more stuff to worry about. P2

Several adolescents felt that their school work was affected by their parent's cancer as well.

> Some of the things that (mom) makes us do - if we have to clean then I worry more about cleaning than like assignments I have to do for school. P4

> I remember at school last year, it was really hard to get like all my assignments you know in on time. P6

> Just like the emotions they can go through. I used to worry more about her (mom) than like my grades. P4

Theme 2: Being There

It was very important for these adolescents to feel they were contributing to their family's well being. They had a desire to help relieve the stress and burden on their

parents and willingly took on extra responsibilities by filling practical and emotional roles.

2.1 Being a "good kid". These adolescents described doing their best to, "try not to be a burden," and "try not to cause a lot of problems." They described helping out by "not causing a lot of drama in the house," and "just need to leave her alone basically", "let her be." They described things like "not complaining" and "try to make the best grades at school" as the best ways to care for their ill parent. One adolescent reflected on why his behavior was so important:

> I'm less defiant I guess like I don't want like there are a lot of people that don't care about their parents, but like I don't want to hurt my mom because I'm afraid that she could be gone anytime so I don't want to mess up our relationship so I'm very careful about that. P5

One teen described his role in the house:

> Mostly you just make sure (mom) is not stressed, make sure if anything is that might bother her is messed up or you just fix it, so she's not stressed that's really the main thing. P9

2.2 Caring for my family. Adolescents also commented on the direct care giving they provided for the ill parent. Older teens especially described a great deal of responsibility for their parents care such as, "taking her to urgent care when it (pain) gets really bad" or "giving her shots for the really bad headaches." Another offered:

> She's a lot more independent now and up a lot more, but when she was in bed probably the first four years after surgery, it was me taking care of my mom and sisters. P9

According to one adolescent:

> (Cancer) makes it hard for her (mom) sometimes, like if she has to think things through a little bit more before doing things. She has a hard time remembering a lot of things, so me and my brother just kind of have to help her through a lot of stuff. P10

In addition to care giving adolescents explained all the household responsibilities they acquired as a result of the cancer. One shared:

> I was kind of, the second parent, the second mom, my dad was there still but - so taking care of everyone and just making sure the house is running okay, with help of laundry, help with anything they really needed to be done, feed the dogs or just the small things that would de-stress (mom) P9

Another offered:

> I just kind of help out with anything that like anyone needs help with, kind of like - if there is something that needs to be done that anyone else can't do then I kind of have to fill in and do that. P7

Theme 3: Managing my emotions

Adolescents described a variety of coping strategies used to deal with the emotions and frustrations brought about by their parent's advanced cancer. Many of them used several different types of strategies to manage their emotions at different times. These included: distraction, talking about it, having a positive outlook, spending time with friends and family, and using existing spiritual and social support systems.

3.1 Distraction. All teens described using a form of distraction at some point to help, "get my mind off of it (cancer)." Others stated, "I like to watch funny shows on Netflix or like go workout or swim or something, hang out with friends you know." and "I just go sit down and play my trumpet anything, just to get my mind off of it." Teens described reading, music, sports and "focusing on different things" to help them manage their emotions.

3.2 Talking helps. Talking about their frustrations or sadness was also a common way these teens coped. They expressed how, "Just talking it out is always really good", "I think it (talking) like releases the stress or like the thoughts that are in my head," and "I will talk to my brother about it (cancer) sometimes, just kind of like, see if we are going through the same things mentally."

Another aspect of this subtheme was the need for some adolescents to explain why parents attempt at 'protecting them' by not sharing information about the cancer was detrimental. Many shared how open communication about the cancer was essential to their continued ability to cope. They took the time to explain how not being told about the cancer caused more distress in the end. As one teen explained:

> I mean it's no use hiding it because you figure out like, if your parents don't tell me, tell you and you, look at your dad and he's stumbling around you ask what happened, then they will have to tell you and then you cry even more. But if they tell you straight up, you like cry and then you just get on with it. P2

Another shared how he felt when his mother tried to protect him from information about her cancer:

> Its hard to ask her because it seems like she just dismisses me really quickly so because she doesn't want it to hurt me, but it just like the wondering it feels like it hurts me more than just knowing what's actually going on. P5

3.3 Thinking positively. Adolescents suggested having a positive attitude is vital to managing their cancer experience. While recognizing that their situations were difficult, some teens found it beneficial to avoid negative thoughts: "Cancer makes it

really hard to be happy with my dad's condition. But I have to make myself be happy and like yeah, just be happy."

Another expressed:

> I mean it's (cancer's) kind of frustrating, but I mean just adding you gotta think positively…this isn't the end of the world. I mean it's sad, but you know we're going to get through it. P2

Some adolescents shared how they learned their positive attitude from their parents: "I mean I have seen how positive they're about it, and it's helped me learn a lot about that." Another shared how his family's faith helped keep him positive:

> My mom has always taught me and my brothers, God does things for a reason and I believe that. So if she ever does go there, I know that it was for a good reason. P3

3.4 Social support. Support from friends, family, church, and school was another vital element to these adolescents well being. Most described having people in their lives that cared deeply for them and understood the challenges they faced. This is illustrated in the following statements:

> I feel a lot more comfortable talking with my friends, especially who understand and I can trust. P3

> I did have a lot of support and people were always asking me how things are going with my mom. I didn't really think people cared and I thought people were just really narcissistic but when I let people know that my mom had cancer then that kind of proved my theory wrong and I learned that people really do care and that they can be helpful. P6

Many of these adolescents' friends were unique in that they also had a parent with cancer. They share how, "they can kind of, comfort you like, they made it through and

you can do it too." These distinct friendships clearly offered a considerable amount of support:

> I have many friends whose parents also have had cancer, and then we share information in many things… it's like, it's totally different because we can relate. P9

> I think like me and my friends we pretty much become a family together because their parents have cancer. So, we are able to talk about like things that bother us and so we built like a relationship with my friends. P4

Theme 4: Positives Prevail

All the adolescents interviewed were able to describe positive aspects of their cancer experience and how cancer transformed them. Most spontaneously reported incidence of growth, appreciation, stronger relationships, and lessons learned by their journey through their parent's advanced cancer. These instances of optimism and encouraging remarks were uncovered throughout the data and came across as the overwhelming tone of these adolescents' experience.

4.1 Personal growth. Adolescents expressed instances when they felt the cancer had, "made the three of us (brothers) stronger." They felt they had increased maturity and sense of independence due to their parent's cancer. As these adolescents offered:

> You should just know that if you have a parent with cancer like, the main thing I've said 100 times you will learn patience, I think that's the main thing, patience and responsibility. P9

> (Cancer) it has kind of taught me a lot of things that I mentioned before, like how to take care of myself. P7

> It totally changed how I was younger like, all adults always told me, I was more mature than any kid, I didn't really believe it, I still don't sometimes like "You're so mature!," "I don't think so." But

> adults think I am, and I guess able to take responsibility and things, and be a leader. P9
>
> I mean I've had to…grow up a little faster you know so I'd be there for my brother. P1
>
> I'm more mature than I would have been because I at a young age I learned how to like take care of my mom, more and like, take on responsibilities of most younger kids wouldn't have. P8

Another aspect of this positive growth was the fact that some of these adolescents became sensitive to other people's feelings and needs. As illustrated in the following quote:

> I guess it (cancer) has just made me kind of realize, like everyone else - like different needs of different people, like I just kind of have to pay more attention to that kind of stuff….you don't understand people until you get to know them and understand what they have done, what they have gone through. P7

4.2 **Increased appreciation.** Adolescents described themselves as different from their peers in their ability to appreciate life and be, "thankful for what we have." Several teens summarized this sense of appreciation:

> I would say it's (cancer is) more of a challenge, but it like helps you kind of grow up more and appreciate everything you have and appreciate life and kind of changes the way you look at things and makes like some of the smaller things more exciting for you. P8
>
> (Cancer) made me a lot more aware of like so many kids take their parents for granted and like its hard for me to do that because I know that she could be gone like any day. P5
>
> I go to family camp, so getting to go with my mom and see her happy, it would make me really happy because she wasn't in pain, but other people see their moms happy like every day, so it's like seeing her happy, would make me happy. P10

4.3 Enhanced relationships. Adolescents reflected on their family's close relationships and how experiencing an obstacle such as cancer allowed them to strengthen their bonds.

> We've (mom and I) become like really good friends now. It's really good…you just trust each other. P1

> Like I said like we built like a stronger relationship, like I notice with other people they are not very close to their parents and they don't really talk a lot to their parents but we all talk to our mom a lot. P4

> I think it's helped me get a lot closer to her (mom) like just be able to talk about deeper things not just, "Hey, how are you doing? Good bye." So we can actually sit and talk about something and it's normal, and you're just now in closer relationship almost like a really good friend relationship. P10

Some adolescents also reflected on their relationships outside of their family stating, "I feel like more loved by more families because of this (cancer) and I got closer to a lot of other families" and "I think me and my friends have gotten closer, kind of like with my family."

4.4 Changed my view of life. Many adolescents explained how their parent's cancer has provided them with a fresh outlook on life and a perspective that is more optimistic. They felt the cancer allowed them to, "opened me up to talk to people," "opened my mind," and "makes me look at life in a different angle…being more an optimist." Cancer allowed them to, "totally look at life in a different way". As one teen shared:

> I feel like my life could have been a lot different. I feel like I could have cared less about things or been really impatient, but after going through all that I'm really patient with everybody. P9

The Lived Experience of Adolescents who have a Parent with Advanced Cancer

The four themes, *Life interrupted, Being there, Managing my emotions, and Positives prevail* constitute the essence of these adolescents' experience with their parent's advanced cancer. Overall, these adolescents report living full lives and using positive coping to make meaning of their family's cancer experience. The adolescents' shared many stories of how their 'normal' lives were interrupted and forever changed by their parent's cancer diagnosis. Their family life contained a steady amount of stress, frustration, fear, anxiety, and uncertainty about the future. They made every attempt to moderate this distress for their family by being there and helping out when needed. Most strived to manage their negative emotions by using multiple coping strategies such as distraction, communication, positive outlook, and peer support. Ultimately they were able to integrate their parent's cancer into their lives, find meaning in the experience, and create value from a devastating life situation. The experience of growing up along side a parent with advanced cancer helped shape these emerging adults into strong and compassionate people with an increased sense of appreciation and gratitude for not only their personal relationships but life as a whole.

Discussion

These finding represent the essence of the adolescent's experience of living with a parent with advanced cancer. The findings in this study underscore the significant impact

an advanced cancer diagnosis can make on a family system. Moreover they provide insight into factors that may play a role in adolescents' well-being.

These results are consistent with previous research that found open communication and the parent child relationship are important factors in the emotional and behavioral adjustment of children to a parent's advanced cancer (Kennedy & Lloyd-Williams, 2009; Sigal, et al., 2003). This study also supported previous findings that adolescents may experience high levels of stress and anxiety when confronted with a parent's terminal cancer (Rainville, et al., 2012; Siegel, et al., 1996b). Furthermore, adolescents reported increased household responsibilities and lack of parental support for daily tasks similar to previous studies (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009). Adolescents in this study reported significant upheaval and stress in their lives as a result of their parent's cancer, yet they concurrently described strategies used to deal with their challenges. The coping strategies described mirrored those found in the literature including distraction, communication about the cancer, social support from peers, optimism and search for meaning (Christ, et al., 1994; Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011; Thastum, et al., 2008). However, this study adds further insight into the mechanisms by which these strategies are effective. For example, adolescents in our study were able to articulate how lack of communication about the cancer increases their distress, "the wondering…hurts me more than just knowing what's actually going on." This study also extends previous findings that a parent's metastasized cancer can have positive consequences in the form of less disruptive behavior by the adolescent (Sigal, et al., 2003). The adolescent's interviewed

were able to articulate their efforts to, *Be a good kid,* by not causing problems or complaining, and doing well in school as a way to decrease their parent's stress related to the cancer.

Having a parent with advanced cancer is especially challenging for adolescents and in some ways subverts normal developmental tasks. Typically adolescents are developing their sense of self and striving for increased autonomy from their parents (Lewis, 2007; Ohannessian, 2007). In addition they are cognitively better able to understand the long term consequences of an advanced diagnosis (Spira & Kenemore, 2000). Many past studies have focused on the negative impact of a parent's cancer diagnosis on the adolescent (Grabiak, et al., 2007; Huizinga, Visser, Van der Graaf, et al., 2011; Visser, et al., 2004). This study offers a description of the experience and reveals how these adolescents simultaneously face uncertainty and fear, and identify areas of positive growth as a result of their parent's cancer. Furthermore, these findings indicate adolescents are able to find meaning in these difficult circumstances which helps shape their growing identity. The theme of *Positives Prevail* is closely aligned with other studies findings of personal growth and positives gained from the experience of a parent's life threatening illness (Kissil, Niño, Jacobs, Davey, & Tubbs, 2010; Wong, Cavanaugh, MacLeamy, Sojourner-Nelson, & Koopman, 2009). These outcomes have been discussed in the literature as post-traumatic growth and take place when children are able to thrive in spite of the challenges they faced during their cancer experience (Arpawong, Oland, Milam, Ruccione, & Meeske, 2013; Wong, et al., 2009). The current study suggests the effect of 'growing up' with cancer as an almost constant part of their

childhood has allowed these adolescents to achieve a certain level of post traumatic growth while still in the midst of the trauma.

Our findings reinforce previous results that suggest the importance of family and peer support, positive attitude, and open communication when a family is coping with advanced parental cancer. Understanding how adolescents gain strength from their relationships with family and peers offers healthcare professionals an opportunity to have services and strategies in place to foster these relationships. For example, encouraging parents to initiate conversations about how their children are coping with the illness as well as providing support and guidance about how to handle these difficult conversations. Moreover, HCP's can offer adolescents a way of connecting informally with peers either at school, online, or through other avenues to allow opportunities for them to form relationships with peers facing parental cancer.

Healthcare professionals should assist adolescents in identifying the impact of their experience with their parent's cancer so they can begin to formulate meaning. The ability to find benefits in a traumatic experience has been positively related to resilience and growth and negatively related to depressive symptoms (Fredrickson, Tugade, Waugh, & Larkin, 2003). Health care professionals and researchers can draw on these results to inform practice and development of interventions that focus on enhancing adolescents' ability to make meaning and appreciate the positivity in life, while coping with a parent's serious illness. HCP's can only begin to develop programs that meet the needs of families facing advanced cancer if more studies identify the needs and concerns unique to this population. Longitudinal studies are needed, using quantitative and qualitative methods

to assess the causal and long term effects of advanced parental cancer on children's adjustment over time. In addition, studies should seek to assess adolescent's quality of life and not just levels of clinical psychopathology. Finally, existing services for children and families who have a parent with cancer must evaluate their interventions using comparison groups and validated measures to assess the efficacy of these programs.

While a parent's advanced cancer diagnosis may be both a devastating and traumatic experience for adolescents this study suggests the experience may also have the potential of creating opportunities for growth and well-being.

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Table 4.1 Participant Demographic Data

Participant	Current Age	Sex	Age at Parent's Diagnosis	Parent's Diagnosis	Notes
1	16	Male	6	Father Brain tumor	Mother early stage brain tumor
2	14	Male	4	Father Brain Tumor	Mother early stage brain tumor
3	15	Male	7	Mother Breast cancer	
4	14	Male	6	Mother Breast cancer	
5	15	Male	3	Mother Breast cancer	
6	15	Female	13	Mother Ovarian cancer	
7	16	Male	16	Mother Brain Tumor	
8	14	Female	6	Mother Brain Tumor	Mother previously Dx. w/ early stage breast cancer
9	17	Male	9	Mother Brain Tumor	Mother previously Dx. w/ early stage breast cancer
10	14	Female	6	Mother Brain Tumor	Mother previously Dx. w/ early stage breast cancer

Significant Statements	**Meaning Unit** **(structures of meaning or themes)**
I think it's (cancer) helped me get a lot closer to her (mom) like just be able to talk about deeper things not just, "Hey, how are you doing? Good bye." So we can actually sit and talk about something and it's normal, and you're just now in closer relationship almost like a really good friend relationship.	Mom and I are good friends because of the cancer. Cancer taught me how to have meaningful conversations with my mom.
I try not to, I try not to be a burden to her. I know she is going through a lot, so I try not to -- I try not to like cause a lot of problems at school, try to make the best grades.	My ill parent is stressed because of the cancer. I try to protect my ill parent from further stress by doing my best at school.
And when she stressed like, I basically was the second mom when my dad was working, I would help my mom get her stuff, I would help my sisters and now that I'm driving in the past year and a half, I drive my sisters everywhere. When I got my permit two years ago, I would drive my mom and sisters everywhere they would need to go, because she (mom) wasn't able to drive.	I was the second parent while my dad was at work. I am responsible for taking care of my ill parent and my younger siblings.

Table 4.2: Selected Examples of Significant Statement and Related Meaning Units

Table 4.3: Example of Two Theme Clusters and Their Associated Meaning Units

Social Support	**Positives Prevail**
My friends all know my mom has cancer.	I understand people better because of cancer.
My friends who also have a parent with cancer understand and "get it".	My brothers and I are stronger because of cancer.
My friends will ask how my mom is doing.	Cancer strengthened my family relationships.
My friends and I are like family.	I appreciate family more.
I have a lot of support.	I appreciate it when mom is happy and not in pain.
People always check in with me about mom's health.	Cancer helps you grow up.
People really do care and that they can be helpful.	Cancer made me more aware of other peoples needs.
My friends I've grown up with, they've gotten used to the fact that my mom has cancer.	Cancer taught me to be patient.
All of my friends have been very nice.	Cancer makes small things more exciting for you.
It brings comfort hearing other people's story of getting through a parent's cancer.	Cancer makes you appreciate life.
	Cancer makes you appreciate what you have.
	Cancer opened my mind.
	Cancer taught me empathy.
	Cancer taught me how to care for myself.
	I can see things form other people's perspectives now.

Table 4.4 Themes & Subthemes

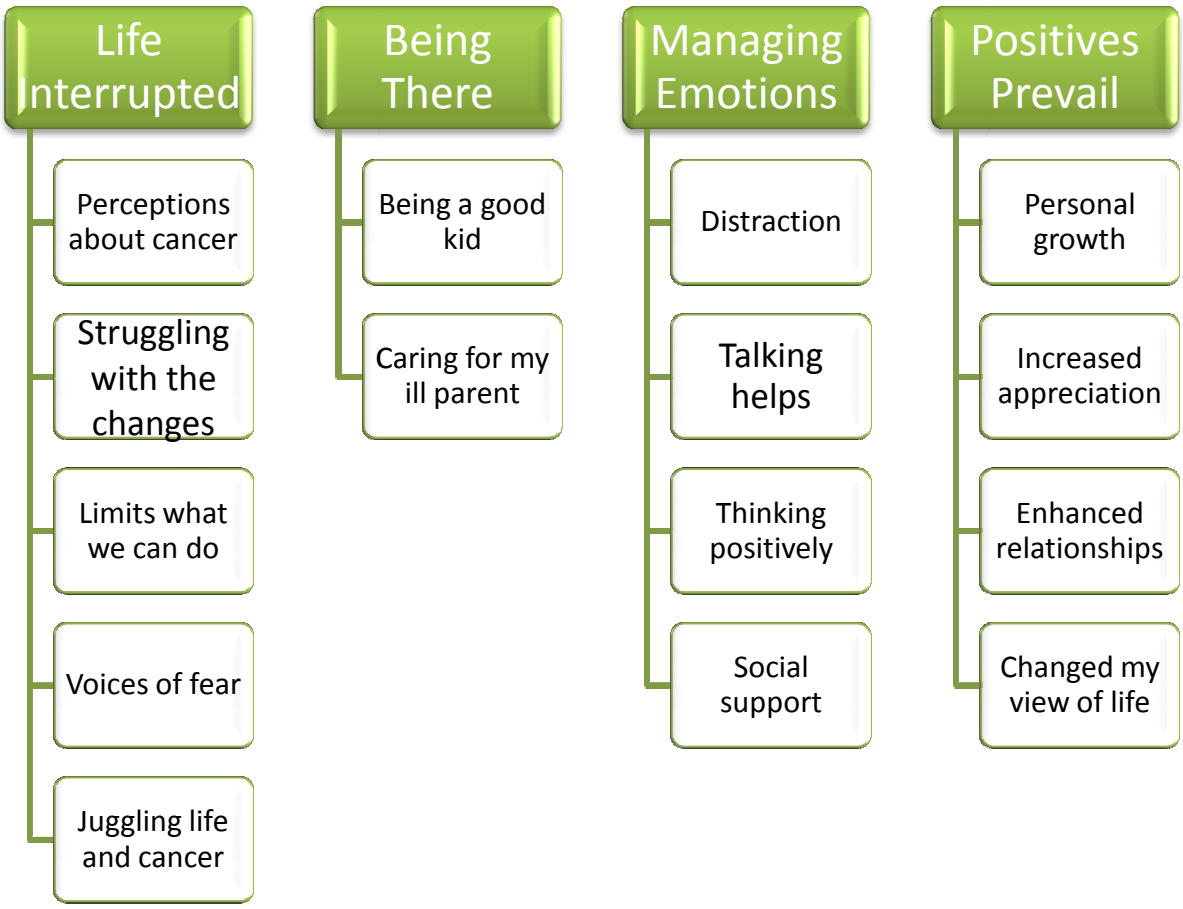

Table 4.5 Adolescent Interview Schedule

"Understanding the lived experience of adolescents who have a parent with advanced cancer"

1. In your own words, describe your parent's cancer.
2. What do you think caused his/her cancer?
3. What questions do you have about his/her cancer?
4. What has your experience been living with a parent who has cancer?
5. How has having a parent with cancer changed your life if at all?
6. How do you want your parent to share new information with you about the cancer?
7. What information do you want about the cancer that you still don't have?
8. If you have questions about your parent's cancer where do you go?
9. What changes if any have you noticed in your parent because of the cancer?
10. What things do you notice about your parent if anything that causes you worry or concern?
11. What if anything is difficult about having a parent with cancer?
12. What has been a positive for you about having a parent with cancer?
13. Is there anything that you do when you're worried that helps you to feel better?
14. What if anything do you do that makes it easier to have a parent with cancer?
15. When things get hard because of your parent's cancer what do you do that helps?
16. How has your parent's cancer changed things with your friends if at all?
17. What if anything do you do with your friends that helps you with your parent's cancer?
18. What concerns if any do you have about your own body because of your parent's cancer?
19. What things are you asked to do now(to help), since your parent's cancer, that you don't mind doing?
20. What things are you asked to do since your parent's cancer that you don't like doing?
21. How if at all are you expected to help care for your parent?
22. How has cancer changed your relationship with your parent, if at all?
23. What if anything does your parent say that helps you with his/her cancer?
24. What if anything does your parent do that helps you with his/her cancer?
25. What if anything does your parent do that makes things harder for you with her cancer?
26. What if anything does your parent do that makes things easier for you?
27. What if anything do you need from your family, or from your parent that you don't get.
28. How is it to talk to your parent when you have a concern or worry about the cancer?
29. What if anything stops you from talking to your parent about the cancer?
30. How often at all does your ill parent check in with you to see how you are doing?

31. How often if at all does your parent check in with you about the support you are getting because of the cancer?
32. What if anything has your parent done to help you get support for the cancer outside the family?
33. What types of services have you participated in with Wonders & Worries? Did you find the services helpful or not helpful and in what way?
34. What type of services or support do you think would be helpful for teens dealing with a parent with cancer? Any advice you would give to other teens that have a parent diagnosed with cancer?
35. Is there anything else you want me to know about your experience with your parent's cancer?

Chapter 5
Conclusion & Implications

This dissertation on the impact of a parent's advanced cancer on adolescents has shown that parental cancer may place a substantial strain on a family's well being. However, it can also be an opportunity for positive growth and adjustment. The diagnosis of advanced parental cancer has the capacity to adversely affect not only an adolescent's emotional and behavioral functioning but also the family's functioning as a whole. It is also possible that family relations may be strengthened or maintained due to various protective factors. However, a portion of adolescents appear to be in danger of psychological morbidity. It seems older adolescents are the most vulnerable to negative psychosocial outcomes. It appears there is also a small subset of these youth that are able to maintain positive levels of adjustment despite the apparent disruptions and emotional strain that a life threatening illness imposes on a family.

Guided by the proposed model of factors, findings presented in this dissertation indicate the negative effects of parental cancer may be mediated by the variation in family adjustment, quality of parent-adolescent relationship, quality of parenting, appraisal of the illness, and adolescent's coping style. These were the most significant factors or vulnerabilities associated with adolescent adjustment. It is also possible that family resources such as a quality support network for the parents and children are significant to overall well being. The studies reviewed suggest the better patient and child perception of social support were the more positive the outcomes were for adolescents. The evidence showed that although family plays a major role in these children's lives, the

amount of external social support (i.e. peers and supportive adults) may also have a substantial position in affecting outcomes. The stress and coping perspective on social support suggests that support plays a role in health by protecting people from the negative effects of stress (Lakey & Cohen, 2000). Perceived social support by peers and supportive adults may promote coping by ensuring less negative appraisals of stress hence buffering the effects of stressful life events (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lakey & Cohen, 2000). This buffering effect can be achieved by the actual supportive actions of others or merely the belief that social support is available. The major findings of this dissertation support the value of open communication between parents and adolescents during a healthcare crisis as a way to strengthen family relationships and decrease anxiety felt by the adolescent.

Major Findings

Article 1 - The results of this analysis of literature have shown the paucity of research on the adolescent's experience when a parent has advanced cancer. From this review of literature we know adolescents' living with a parent's advanced cancer show significantly higher levels of distress, anxiety and depression as well as lower self esteem than their peers (Rainville, et al., 2012; Siegel, et al., 1996b; Siegel, et al., 1992). These findings suggest the end stages of a parent's illness may be a particularly vulnerable period for adolescents. From the reviewed studies we know parents are concerned about the best ways in which to talk about their advanced cancer with their children; try hard to maintain normalcy in their children's lives; strive to be good parents; and are concerned

about the emotional impact their cancer has on their children. Most studies discovered families facing advanced cancer employ positive outlook and hope as strategies to overcome the challenges and uncertainties of their experience. As a result possible resilience or protective factors were identified.

However, there is still much we do not know about the experiences of adolescents living with a parent with advanced cancer. We lack studies that examine the specific concerns parents have about their adolescent children's behavior; an understanding of the adolescent's experience from their own perspective; the difficult situations faced by the adolescents in relationship to the parent's advanced cancer; the parent-adolescent relational issues; and what parent's tell their adolescents about advanced disease diagnosis. Therefore, more descriptive research focused specifically on adolescents is needed to inform development of effective interventions for this at risk population.

Article 2- The second article illustrates how adolescents manage a long term illness such as a parent's advanced cancer. The core construct that organized study results from the adolescent interviews was *weaving a normal life with cancer*. The progression of the advanced disease was slow and occurred over many years for these families. Thus, many of the adolescents described 'growing up' with their parent's cancer as a part of their lives. The adolescents recognized the fact cancer was beyond their control and they could not make it better. As a consequence, they made every attempt to live a normal life despite the cancer. They created ways to live with it as part of the background rather than a constant focus of their attention. Although the possibility of losing their parent was an

impending fear, it was impossible for them to live in a constant state of crisis and apprehension. For that reason the adolescents and their families utilized various coping strategies to allow them to continue moving forward with cancer as only one piece of their life story.

Article 3 - The third article support the previous findings in this dissertation but also touches on the strength and resilience some adolescents and families can demonstrate when well supported. These findings reinforce previous results that suggest the importance of family and peer support, positive attitude, and open communication when a family is coping with advanced parental cancer. This study offers a description of the challenges of the adolescent's experience and reveals how they simultaneously face uncertainty and fear, and identify areas of positive growth as a result of their parent's cancer. Furthermore, these findings indicate adolescents are able to find meaning in these difficult circumstances which helps shape their growing identity. The theme of *Positives Prevail* is closely aligned with other studies findings of personal growth and positives gained from the experience of a parent's life threatening illness (Kissil, et al., 2010; Wong, et al., 2009). This study suggests the effect of 'growing up' with cancer as an almost constant part of their childhood has allowed these adolescents to achieve a certain level of post traumatic growth while still in the midst of the trauma.

Discussion

Researchers and healthcare professionals can utilize these findings related to risk and protective factors to better understand the relationship between advanced parental

cancer and adolescent outcomes and use these to inform development of clinical interventions. Moreover, intervention researchers and health care professionals need not wait until all the variables affecting families living with advanced cancer have been unmistakably identified (Pedersen & Revenson, 2005). Despite the important descriptive research already completed in this field there is a lack of intervention research (Christ, 2006; Compass, 1994, 1996). Rigorously evaluated interventions based on existing research and well developed theory would provide much needed relief to adolescents struggling with advanced parental cancer and may shed light on some of the underlying mechanisms described in the proposed model.

Concurrently, in order to present individualized care for adolescents and families a family centered care approach is essential in cancer care services. Recognizing the impact of cancer on the lives of patients, their partners, children, adolescents and the family as a whole is an essential factor in providing appropriate and adequate psychosocial services to families facing advanced cancer. Families are an integral part of a patient's experience in dealing with illness and treatment, just as the family has a significant role in providing support for the patient, the entire family unit is affected physically, emotionally, socially, and psychologically when a family member has cancer (Mitschke, 2008). Healthcare professionals (HCP) must be cognizant of the long term implications an advanced cancer diagnosis has on the entire family including dependent children and adolescents. Thus the first step in making a thorough assessment of patient needs is to include any parenting concerns they may have.

There are several other direct implications for social work and HCP's practice that arose from these studies. Generally, adolescents and their parent's desire some guidance in navigating the new and unexpected experience of facing the parent's impending death. This support is distinct from support they may have received at the beginning of the cancer diagnosis. Clinicians should be aware that friends are a major source of support and should appreciate their contributions by including them in adolescent support services or providing services to schools directly. HCP's may also use these findings to tailor interventions that would be most effective for the population of families they are supporting. Clinicians need to convey empathy and understanding and help adolescents begin conversations with the ill parent about their needs and concerns. Additional suggested services include creating informal opportunities for adolescents to meet and engage with other youth facing parental cancer, encouraging and modeling open communication among family members, expanding families coping styles and providing developmentally appropriate cancer education for adolescents should all be aspects of quality oncology care for parents of dependent children.

It is important to note that the parents of the adolescents participating in these studies were predominately married, well educated, and from middle to high SES households. These factors may have affected their ability to cope with a serious illness and deserve consideration in future studies. Ultimately, families affected by a parent's advanced cancer diagnosis should have access to professionals who are knowledgeable and available to address the psychosocial concerns of the entire family.

Limitations

Qualitative research does not use limitations, rather it emphasizes strategies for trustworthiness as a basis to evaluate rigor. The basic quantitative concepts of reliability and validity are not appropriate to address when assessing the qualitative studies in this dissertation, instead the relative trustworthiness and authenticity of these studies will be addressed as well as the strategies used to achieve rigor. The concept of quality or rigor in qualitative studies has been an issue of controversy for some time (Creswell, 2007). Armour et al. (2009) described rigor as "the degree to which researchers hold themselves to standards of inquiry that address challenges to the credibility of the studies findings."(p.102)

Lincoln and Guba (1985) suggested the concept of trustworthiness as a way to ensure quality in naturalistic research designs. Since then, qualitative researchers have put forth various criteria that can be used to assess a studies authenticity or trustworthiness and strategies that can be used to achieve rigor (Creswell, 2007; Johnson, 1997). Creswell (2007) recommended researchers employ at least 2 of these strategies in any given study to achieve adequate trustworthiness of their findings. The following is a summary of the strategies used in each of the studies included in this dissertation.

Article 1: **Adolescent's Living with a Parent with Advanced Cancer: A Review of the Literature**

A systematic review like any other type of research is subject to bias, an effective review applies rigorous methods that are thoroughly reported (Gough, Oliver, & Thomas,

2012). In a systematic review, all methods including inclusion and exclusion criteria should be explicit, allowing the reader to determine the quality of the review process. Therefore, the researcher made every attempt to remain transparent in this review of literature and offered a critique of the literature included.

Article 2: **Weaving a Normal Life with Cancer: Adolescents Experiences When a Parent has Advanced Cancer**

The researchers used the following strategies to ensure trustworthiness of this paper.

Peer review- coding decision based on complete agreement of 2 authors

Reflexivity - through bracketing of assumptions and naïve reading of data

Low inference descriptors - used participants own words and direct quotes whenever possible **Methodology** - reported in detail

Methods triangulation- use of standardized measures as well as qualitative interviews; researcher remained blind to quantitative results until completion of qualitative analysis

Reliability - all transcriptions were checked for accuracy

Article 3: **Life Interrupted: The Lived Experience of Adolescents who have a Parent with Advanced Cancer**

The researchers used the following strategies to ensure trustworthiness of this paper.

Peer review- discussion of the researcher's interpretations and conclusions with two "disinterested peers"

Reflexivity - through bracketing of assumptions and naïve read; peer review during the process of data collection and recruitment to clarify bias; field notes

Low inference descriptors - used participants own words and direct quotes whenever possible **Methodology** - reported in detail

Reliability – good quality recordings and transcriptions; 100% of transcriptions were checked for accuracy; computer programs to assist analysis and coding

Rich thick descriptions- to allow readers to assess transferability

Although these qualitative studies consist of small, relatively homogeneous sample sizes that limit the transferability of the results, this research builds a foundation for deeper exploration. This would include studies of more culturally, and geographically diverse families and adolescents recruited from various settings.

Recommendations

There are still large gaps in the literature on adolescent's adjustment to advanced parental cancer. This dissertation aimed to highlight challenges in this area to inform future research. The following recommendations are offered:

- Longitudinal studies are needed to assess the causal and long term effects of advanced parental cancer. In addition, longitudinal designs will allow for a better understanding of how adolescent's adjustment may change over time (diagnosis, treatment, and beyond).
- Studies with a more narrow focus with respect to developmental stage (early and middle adolescence), and illness characteristics or results that make distinctions based on these considerations. This can also be accomplished using larger samples with the opportunity to compare subgroups.

- Assessing adolescent's quality of life and not just clinical levels of psychopathology are needed.
- Triangulating data collection in the form of methodology (quantitative and qualitative), informants (adolescent, parent, teacher, HCP) to increase reliability.
- Focus on identifying risk and protective factors that affect adolescent outcomes.
- Intervention studies using control groups and validated measures to assess the efficacy of programs.

Future Research Agenda

Gratitude as an Intervention for Adolescents Affected by Parental Cancer

"Until we realize that things might not be, we cannot realize that things are. Until we see that darkness we cannot admire the light…" (Chesterton, 1905 as cited in Frias, 2011, p.154)

This quote by Chesterton eloquently suggests that once a person is able to recognize 'things that might not be', they can begin to develop a true appreciation for these things. Frias (2011) suggests an important element to a grateful person may be their understanding that life is a benefit and not a given. The experience of a parent's advanced cancer provides an opportunity for the adolescent to imagine their life without the ill parent and paves the path for a deeper appreciation of their family. The themes of positive growth and gratitude that emerged from this dissertation suggest this is a potentially powerful protective factor adolescents use to maintain positive adjustment during a parent's protracted illness. This information can now be used to closely

examine the potential for gratitude as a construct in intervention programs for families facing parental cancer.

Research has shown gratitude contributes to psychological and social well being and mental health (Wood, 2010). There is now consensus that grateful individuals tend to be happy and gratitude may cause enhanced subjective well being (Wood, et al., 2010; Wood, et al., 2008). Recent studies have also shown gratitude in adolescence is related to positive psychological outcomes (Froh, Sefick, & Emmons, 2008). From the results of this dissertation we can hypothesize that some of the adolescents used generalized gratitude as a coping strategy that may have protected them from psychological and emotional problems related to their parent's advanced cancer diagnosis. The various characteristics of gratitude as outlined by Wood and colleagues (2008) are closely aligned to positive aspects found in our studies such as: (1) appreciation of other people, (2) a focus on what the person has, (3) behaviors to express gratitude, (4) focusing on the positive in the present moment, (5) appreciation rising from understanding life is short, and (8) positive social comparisons.

Frias and colleagues (2011), examined 'exposure to difficult circumstances' as a possible gratitude development mechanism. Specifically, they focused on how life threatening circumstances might enhance gratitude. They found that people who were forced to reflect on their own death showed significantly increased gratitude compared to controls. Thus supporting the theory that becoming aware of one's mortality enhances gratitude for life (Frias, Watkins, Webber, & Froh, 2011). Adult oncology researchers

have begun to examine how gratitude in the general population is an important predictor of psychological well being and are making attempts to link and utilize gratitude to address the needs of patients with life threatening cancer (Algoe & Stanton, 2012; Ruini & Vescovelli, 2012).

Future research on this dissertation topic can examine the hypothesis that a parent's advanced cancer may allow adolescents to reflect on their parent's death, their own mortality, and, as a result, enhance their gratefulness and appreciation for their family and their current life. The goal of this research agenda would be to draw on findings related to the use of gratitude as a coping strategy and a potential protective factor in order to inform development of clinical interventions that help to enhance gratitude in adolescent's dealing with a parent's cancer. Its aim is to create an intervention that encourages gratitude enhancing activities for families facing serious illness as a way to build psychological resiliency and prevent maladjustment.

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